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ABSTRACT

The first four volumes of the "Coalition Quarterly" journal are compiled in this document designed as a management resource for consumer organizations (especially parent coalitions) that operate centers for families of handicapped persons. The introductory issue describes the intent of the publication, proposed topics for future issues, and the background and history of parent coalitions and early parent centers. Necessary first steps in formally establishing a parent center are described, and issues including philosophical assumptions, their embodiment in organizational structure, and the need for a legal structure, are discussed. Volume II discusses personnel management as it applies to staffing the parent center including issues governed by law and common personnel practices that have evolved among parent centers. Basic information about nongovernmental funding sources available to coalitions and organizations representing people with disabilities and information about federal and state government funding sources is also provided. Volume III focuses on federal government standards for management of funds received, specifically addressing topics including documentation of monies disbursed, and use of federal audit standards. Additional issues in this volume discuss volunteer resources and introduces the Education of the Handicapped Act Amendments of 1983. Finally, Volume IV reviews recent legislative initiatives in the field of special education and vocational rehabilitation. (AA)

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COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

Volume I, Number 1 *Winter 1980*

INTRODUCTORY ISSUE

Funded under Contract No. 300-80-0859 of the U.S. Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education.

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INTRODUCTION

Coalition Quarterly is designed as a management resource for consumer organizations, including parent coalitions, that operate centers for families of handicapped people. Within each coalition there are individual parents and other advocates who bring their own unique perspectives and sensitivities to the goal of improving life for persons with handicaps. Not all, however, bring a full acquaintance with the tasks and problems involved in creating an organization that will enable them to achieve their goals. The purpose of this project is to supply as much as possible of that needed management information.

By collecting, synthesizing, and disseminating the wealth of management expertise that parent centers have accumulated during the past ten years, we hope to support and enrich newly forming centers. We will define the problems, identify some resources, and identify some possible solutions. Options and best practices which have proven useful will be discussed and their application to a variety of situations and organizational models will be suggested.

Forthcoming issues of Coalition Quarterly will offer selections written by parent leaders throughout the country who will describe firsthand both the problems they have encountered and the solutions they found. You will see the importance of flexibility and commitment as these leaders apply innovative strategies to suit the unique political and social climate of their communities.

There are basic problems common to all centers. When addressing these, we will give concrete, "how-to-do-it" information. In order to provide comprehensive, relevant information we also need input from the "grass roots." Let us hear from you. Let us know what topics would be most informative, stimulating, and helpful to you. Consider yourself a primary contributor to future editions and help us improve them.

Although our use of the term "parent centers" indicates the primary audience for whom this publication is being prepared, we hope that much of the information will also be useful to a larger audience of organizations serving handicapped people and their families.

BACKGROUND

The decade of the nineteen seventies brought about revolutionary changes in the education of and related services for handicapped children. Change came through cases in the federal courts (PARC, Mills), through new state special education laws, and finally through powerful federal

laws: the Education for All Handicapped Children Act (P.L. 94-142) and Section 504 of the Rehabilitation Act. Crucial to these changes has been a drastically changing role for parents of the children to be served. The new mandates give parents rights and responsibilities for which they have never been prepared, just as most have never been prepared for the role of parenting a handicapped child.

Parents of handicapped children were prime movers bringing about these improvements, although the most optimistic were surprised by the speed with which change occurred. Consequently, even those parents who pushed hard for the changes were scarcely prepared to assume the new responsibilities required of them on behalf of their own children. Partly through personal experience, parent leaders around the country quickly realized that if these dreams were to be realized, if the laws were to be fully implemented, large numbers of parents must receive information and training in order to access their newly gained rights and to perform their responsibilities.

It also became clear that parents of children with various disabilities shared more similarities than differences in their experience as parents; they needed to form a new kind of organization that would benefit all handicapped children, rather than limit their efforts to particular disability interests and continue to compete with each other for legislative and fiscal improvements. Thus, parent leaders in many sections of the country came together in their own state or metropolitan region to formalize coalitions consisting of parents whose children had a variety of handicapping conditions.

From region to region the coalitions have varied in detail; some have only organizations as members, some have only individual persons as members, and some have both groups and individuals as members. Some include organizations of diasabled adults and other consumer advocates; others include primarily parents. They vary in other details of history and manner of functioning. However, they all share three characteristics: they cut across disabilities, they are run by and for parents of handicapped children, and they have as their large overriding goal the promotion of services for handicapped children and their families, with decisions about those services based on genuine input from the families affected.

Since the pilot project in 1975, several parent coalitions have received funds from the Bureau of Education for the Handicapped and from a variety of other sources to enable them to operate centers to provide information, training, and many other services for parents of handicapped children. There was official recognition that parents needed information and training in order to effectively participate in new special education processes.

When the early parent centers were established, experienced staff members at Closer Look (the National Information Center for the Handicapped) gave valuable technical assistance on the operation of information and referral projects. Also, from the beginning, the leaders of parent centers have enthusiastically helped each other as much as possible. As the parent centers have grown, proliferated, and become involved in a wider range of programs, new needs in management have emerged. These needs have often transcended those encountered by an organization limited to information and referral. Leaders of the parent centers have worked and continue to work closely with each other, and with the staff of Closer Look, trying to solve problems together by brainstorming and sharing experiences. It is our hope that Coalition Quarterly will offer a more formal and more efficient method for collecting and disseminating the specialized management information needed by parent centers.

PROSPECTUS

Basic Format and Overall Content

This is the first in a series of twelve issues which will be produced over the next three years. We will utilize a monograph format and each quarterly will address two or more related topics.

A preliminary survey of parent centers has identified some of the topics to be included. The format, however, is tentative and will be adapted to suit the needs expressed by our readers.

Volume I is an overview of the management problems that were identified in our survey of parent coalitions. These problems are examined in three major groupings: (1) organizational problems that face any similar operation; (2) problems arising from the unique history of coalitions; and (3) problems specific to the operation of these particular centers.

This first issue contains background information, a discussion of the six topics to be included in the next three quarterlies, and an invitation for readers to respond with additional topics. The following three issues (Numbers 2, 3, and 4) will lay out the problems and present some solutions that have worked or examples of other possible remedies. (These topics will be discussed in detail below.)

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Volume II will summarize best practices and expand upon the material outlined in Volume I. For example, a discussion of varying ways to organize coalitions will include several

INFORMATION IS POWER!

Let us know what information is most needed by your organization at this stage of operation. The more responses we get from you, the more representative our information will be and the better suited to your needs.

Following is a checklist of management areas that you or your staff may need to acquire or improve upon:

case management _____
contract management _____
financial management _____
personnel management _____
planning accounting for non-profits _____
affirmative action _____
working with boards _____
conflict management _____
crisis management _____
decision making _____
legislative process _____
time management _____
legislative process _____
time management _____
volunteer recruitment ___
staff evaluation _____
program evaluation _____
public relations _____

OTHER: _____

_____

_____

Your Name: _____

Name of Organization: _____

Address: _____

_____

Phone: ( ) _____

What services are provided by your organization? _____

_____

_____

What is your professional role? (Administrative, direct client service, financial, supervisor, other?) _____

_____

_____

Federation for Children with Special Needs
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different annotated model bylaws. For the center operated by a coalition, organizational charts will be developed to illustrate variations in size and complexity. A section on funding will include an up-to-date list of funding sources, suggested outlines for proposals and examples of model budgets. A plan for affirmative action, a model set of personnel policies, and a plan for implementing Section 504 of the Rehabilitation Act will also be included. These will be based on actual, successfully implemented examples. Finally, in an effort to standardize record keeping and documentation among the centers, the Coalition Quarterly will offer examples of various forms that have proven useful, i.e. intake forms, travel and expense sheets, weekly time schedules.

***

Volume III, Numbers 1 and 2 will report on additional options that have been identified during the previous months. Number 3 will examine the possibilities and problems of developing a more formal relationship among parent coalitions. We will begin to apply the best practices in specialized management described in earlier editions to the inter-relationship of the centers nationwide. The final issue will deal with the role of experienced parent centers in replication in geographical areas where there are no centers. The Coalition Quarterly will stress the importance of a cooperative effort that is possible only through coalition building, bringing together groups that otherwise would duplicate efforts or even compete against each other.

***

Specific Topics for Volume I

The next issue (Volume I, Number 2) will consider the task of formalizing organization. Content will be presented in two sections: "Necessary First Steps" and "Resources Available to Parent Centers."

Before taking the legal steps required to formalize their organization, it is necessary for the coalition to clearly articulate and put into writing those assumptions that are shared by the group. These shared values will determine the group's goals and objectives. They will also point the way to a structure that will promote rather than diminish the group's overall purpose. The following elements of basic organization will be discussed as well as their implications:

Incorporation
Non-Profit Status
Tax-Exempt Status
Bylaws
Fiscal Management
Record Keeping and Documentation
Reporting Requirements

We will examine options, list help that is available and resources that should be explored. Wherever possible, sample forms for documentation and sample budgets will be presented as well as suggestions to simplify the tasks and save time.

The section on "Resources" will examine two types of centers, those operated primarily by volunteers and with limited resources, and those centers that have felt the need to raise sizeable amounts of money, largely from grants.

One coalition has deliberately chosen not to accept government funding of any kind. The director of that coalition will describe the advantages and hazards of such a decision as it has worked for that group.

A discussion of the funded centers will concentrate primarily on problems that funding presents to parent coalitions:

- avoiding competition with member organizations;
- avoiding restrictions that too narrowly limit activities;
- maintaining the flexibility to allow a change in emphasis without drastically altering activities.

We will emphasize the importance of operating with a variety of funding sources and cite examples of successful efforts of this kind. References will be made to available publications on fiscal management and resources.

***

Volume I, Number 3 will focus on advocacy and the relationship of the center with other organizations. These areas have presented problems that are specific to the operation of parent centers. Advocacy issues will be examined in two areas: case advocacy and issue advocacy.

Case advocacy is defined as one trained parent helping another parent to access services for his/her handicapped child. A committment to this type of individual advocacy poses several problems:

- There is a danger of developing a new dependency system rather than encouraging parents to develop their own resources.
- Advocacy organizations, once they become known, are often deluged with more requests than they can adequately handle.
- Most staff members, as parents of handicapped children themselves, are strongly committed and, therefore, they are particularly vulnerable to "burnout."

- It is usually not cost effective to provide one-to-one service, especially if that is the only or primary function of the staff.

Various centers will prepare articles describing the strategies they have devised to solve some of these problems. There will also be a brief article on ways to establish a system of paralegal advocates to represent parents in formal administrative hearings.

The purpose of issue advocacy is to effect changes in existing mandates, policies, and procedures. By using individual cases for ongoing needs assessments, many centers have learned to spot systemic problems, and taken steps to change the system rather than to continue solving them on a one-to-one basis. Another form of issue advocacy is parental input in policy making. Some of the issues in advocating for system or policy changes that will be highlighted are:

- the development of expertise necessary to affect policy;
- the value of litigation and issues to be considered;
- situations and local conditions that help determine strategy;
- the importance of documentation; and,
- how much and what kind of lobbying can be justified.

Success stories of this type of advocacy will demonstrate how local situations determine strategies.

Among the questions involved in systemic advocacy are those concerned with a coalition's relationship with other organizations. In general, groups working on behalf of handicapped children want to cooperate with other organizations, but that goal is not always easy to achieve. The Coalition Quarterly will offer information on:

- stategies to avoid duplication of effort;
- ties with organizations of disabled adults;
- how to encourage parents to become involved with the parent organization that best represents the interests of their child;
- the relationship of center's staff with member organizations;
- the role of board members in the center and with other groups;
- interaction of staff members with other organizations, ie., what is center related and what is not.

Issues pertaining to personnel policies and practices for paid staff and for volunteers will be discussed in Volume I, Number 4. For example, hiring practices are sometimes complicated by the unique history of these organizations: most centers were started by volunteers who were parents of handicapped children. In making the transition to a paid status there may be a tendency to hire "professionals" and overlook the original volunteers. Furthermore, funding limitations sometimes limit the number of paid staff, and thus some staff must remain in a volunteer capacity. There are issues that must be considered in a hiring policy of preference for parents of children with special needs. Other elements of staff management as they relate to parent centers include:

- timely payment of employee taxes;
- state and federal labor practices;
- overall policies regarding sick leave, vacation, holidays and other employee benefits;
- policies for part-time employees;
- staff development and training;
- staff evaluation and rewards;
- participation in short and long-term planning;
- use of consultants.

Volunteer services have been a valuable resource used by many centers as a way to expand their effectiveness. Centers will be asked to report on their successes with volunteers, including retired persons, parents, students, trainees in sheltered workshops and vocational training programs. There are possibilities and limitations among all groups and it is important to keep these in mind when setting expectations. Sometimes rewards are built into the job; for example, students on field placement who receive course credit. Ways to offer rewards when they are not built into the job will be explored.

FOLLOW-UP ASSISTANCE

In the event that the information contained in the Coalition Quarterly stimulates further questions or a need for more in-depth information, please call or write to us at the Federation. We will do our best to provide you with the assistance you need. Contact:

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COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

Volume 1, Numbers 2 and 3 September, 1981

NECESSARY FIRST STEPS

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This issue of Coalition Quarterly is devoted to the nuts and bolts of formally establishing a "center" that will offer information, training, and/or other services to families of handicapped children or adults. The discussion will emphasize the relationship between philosophical assumptions and the formal decisions that must be made around the legal requirements for incorporation, tax exempt status, fund raising, and actual operation of such a center.

PHILOSOPHICAL ASSUMPTIONS

In forming coalitions across disabilities, parents do not intend to make obsolete the efforts of the many community organizations promoting the welfare of people with particular handicaps. Wherever there are issues of common interest to all groups, the coalition works to coordinate activities, to avoid duplication and to provide generic services for families of handicapped children.

Central to the operation of parent centers is the careful and clear articulation of shared goals and values. In general, each newly operating center has tended to move along full steam ahead to serve as many parents of handicapped children as possible without giving much thought to its underlying philosophy. There is, of course, an obvious tendency for like-minded people to join together in the first place. However, experience has shown that it is important to take time out at an early point of operation to examine carefully the philosophical assumptions that are guiding the work. Such an examination can accomplish several goals: force the organization to think through the bases on which their everyday activities are founded; help the staff prioritize their work; and uncover any areas of important disagreement that may have gone unnoticed.

Preeminent among the philosophical assumptions shared by the parent centers now in operation is the importance of maintaining and promoting the parent's perspective at every level: parent to child, parent to parent, and parent to professional and policy maker. Parents are recognized as valuable resources, offering insight and solutions for their children's best interests. They are seen as equally effective in their contributions toward the design, implementation and evaluation of public policy. Underlying this attitude is a commitment to the informed participation of all citizens in all stages of the policy-making process. This commitment reflects a national trend which supports the contributions of all segments of society in advocating for consumer input into those policies affecting one's own life.

In addition to this shared view about the importance of parents as "consumers," parent coalitions also share a fundamental philosophy about handicapped persons. Coalitions have used various techniques to articulate their philosophical assumptions. For example, during the fifth year of operating a center, the Federation for Children with Special Needs hired a consultant to help staff and board members prepare a long and short term plan for the organization. The consultant, Dr. Robert Audette, began by helping participants articulate the philosophical assumptions that had guided the activities of the center. Most of

the views described in Dr. Audette's report are widely shared by parent coalitions across the country:

> "The Federation not only believes that individual differences in people are normal but that these differences should be valued. While disabilities are not sought-after differences for any person, the Federation believes that disabilities provide children and adults with unique perspectives, insights and abilities which contribute to the quality of relationships between individuals as well as to the overall well-being of society. Consequently, they hold all persons, regardless of the severity or type of disability, to be completely and beautifully human and important members of society.
>
> "Along with the high value which the Federation has for persons with handicaps is a belief in the value of children. Children are held by the Federation as the hope for the evolving improvement of humankind. Children are simultaneously the opportunity for the betterment of society and the vulnerable victims of its short-sighted policies. Consequently, the Federation places great value on the family as a caring protector of children's vulnerability, as well as a catalyst for their healthy growth and development. Because parents are the leaders of families, the Federation places a tremendous value on the contributions parents can make toward supporting the health and development of their children at home as well as in society.
>
> "Finally, the Federation believes that the development, implementation, and evaluation of public policy should have the informed and active participation of all citizens. To this end the Federation for Children with Special Needs promotes the active and informed participation of parents of children with special needs in caring for and supporting their children at home, in their neighborhoods and communities, and particularly in shaping, implementing and evaluating public policy which affects them."*

This articulation of philosophy has assisted the Federation and the other parent centers in the national network in developing and promoting such additional goals as the following:

A. At the local level, establish parent groups in every community with the capacity to:

   1. Impact on community policy affecting handicapped persons.

   2. Advocate on behalf of individual families regardless of income.

   3. Recruit and train other parents and interested persons in promoting similar values.

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* Audette, Robert. "Report to Federation for Children with Special Needs for Developing Five-Year Plan," March 1979.

B. At the state level,

1. Expand the age range of the entitlements that are now guaranteed by special education laws.

2. Extend membership and benefit opportunities to other, often doubly, disenfranchised groups -- for example, minorities, poor, migrant, etc.

C. At the national level,

1. Promote a noncategorical approach to special education and other services for handicapped persons.

2. Establish a strong network of parent centers througout the country.

3. Increase opportunities for participation by parents in federal policy decisions concerning their children with special needs.

Although there are differences in style and emphasis from coalition to coalition, most share the philosophy outlined above. Their common challenge has been to effect a major public attitudinal shift from assumptions about the incapacities of people with handicaps to a positive focus on a person's capability. This shift is gradually being achieved by reducing or eliminating historically discriminating restrictions in the political, social, and physical environment.

EMBODIMENT OF PHILOSOPHY IN ORGANIZATIONAL STRUCTURE*

Once the members of a coalition decide that in order to deliver the services needed by the families they represent the coalition needs substantial material resources, they then must make several decisions that are required by law and that should be shaped by the underlying philosophy. Although the obvious meaning of the term "material resources" is money, that term may also mean a variety of other things: free space, donated equipment, volunteer time, professional advice and services, for example. Solicitation of donations, whether money or goods, is greatly facilitated by the possession of tax exempt status and by careful adherence to the rules imposed by that status.

1. Need for Legal Structure

Once a coalition decides to operate a center requiring space, staff, equipment, and supplies -- no matter how small the operation -- the organization must meet the requirements of local, state, and federal governments. In order to meet those legal requirements, it is necessary to create a structure which is, in many ways, similar to a business. Through this structure, the coalition can legally manage money, personnel, and taxes, and thus meet the costs of delivering the needed services -- a newsletter, a hotline, parent training, for instance.

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* This section has been prepared by Attorney David Trott, who has served as a legal consultant to several parent centers.

2. What Structure?

Leaders of existing parent centers, supported by their attorneys, strongly recommend that coalitions intending to operate centers take the steps necessary to become incorporated. The major benefits of that step are as follows:

a. Limited Liability

If an individual personally orders envelopes from the stationery store, and then is unable to pay for them, that individual is responsible for the debt. As a more dramatic example, the director of a parent center might contemplate signing a one-year lease for office space at $600 per month. If a corporation makes such arrangements (and does not deceive or commit fraud in doing so), individuals are not held to the contract, the corporation is. Individuals are not held responsible for the debts and liabilities incurred by the corporation. The corporation serves as a mechanism which allows people to start something new without risking all of their personal assets if the operation does not work out.

b. Credibility and Accountability

The landlord renting office space wants to know that some entity is responsible for paying the rent. A corporation, registered with the state, with its own bank account and legal assistance, is assurance that contracts entered into will be duly honored. Similarly, if dues are collected, donations solicited, or newsletter subscriptions sold, the center is obligated to inform the state attorney general and tax officials. Agencies of government charged with protecting the public interest are concerned whether the money is going to an individual person or is being collected for specific, limited, publicly authorized purposes and is being held separately for those purposes, as required by a group's corporate existence.

3. What Kind of Corporation: Non-profit and Tax Exempt?

The nature of a corporation established for a parent center is obviously different from that of a profit-making business. Unlike General Motors, parent centers will not make profits, distribute dividends, or sell stock. Salaries and expenses need to be met, but parent centers typically do not seek a profit.

Most states have specific laws allowing groups to establish a "non-profit" or "not-for-profit" corporation. The legal requirements are usually much simpler and the filing fees are much lower than those for businesses intending to make a profit.

The primary reason for establishing a non-profit corporation, however, is federal tax law, specifically those requirements relating to the most likely sources of funding for coalitions -- donations, charitable foundations, and government agencies. If the corporation is non-profit and if it meets other requirements, it can qualify for tax-exempt status under federal tax laws.

Since there are occasional misconceptions, it is worth noting that, by law, being non-profit does not automatically mean being tax exempt; acquiring tax exempt status is, in fact, a whole separate process.

a. Advantages of Tax Exempt Status

A tax exempt corporation pays no taxes on its earnings or profits. It is possible for a corporation to be non-profit but still have occasional profits, or net earnings. If such a corporation is not tax exempt, it would have to pay taxes on those earnings, however small or infrequent. Since parent coalitions operating centers are likely to have few profits, this advantage is of little concern.

More significant, though, is the fact that tax exempt status also frees the organization from a variety of other tax obligations, including sales and real estate taxes in most states. It does not, however, relieve the corporation from all taxes. For example, the tax exempt corporation must pay the federal excise tax on telephone use.

Most important, of course, is the obvious fact that only with tax exempt status can an organization be eligible for various funding sources. Many federal and state government contracts and grants, especially in the health, education, and human service areas, cannot be awarded to for-profit corporations. In applying for such funds, federal tax exempt status is proof positive of eligibility.

Private charitable foundations are a frequent source of funds for coalitions. These foundations are often interested in funding services for disabled children. They are themselves tax exempt and cannot give their money to another organization unless it also is tax exempt.

Tax exempt status is crucial for coalitions that choose to rely heavily on donations. A person, group, industry, or other donor will receive a tax deduction for a gift to the coalition only if the coalition is tax exempt, and only if the organization has the particular form of federal tax exempt status that allows tax deductions for contributions µ501 (C)(3)ß. Obviously, donors are encouraged to increase the size of a gift if they too can benefit from the contribution by reduction in federal and state taxes. As a qualified tax exempt organization, a coalition assumes the same tax status as a church or hospital, and fund raising is greatly facilitated.

b. How To Do It

Once the decision has been made to establish a non-profit, tax exempt corporation, several related steps should be taken. All experienced parent center directors concur that legal assistance must be sought for the formal incorporation process. Frequently such assistance has been donated by a parent or friend who is an attorney. However, coalition leaders agree that paying a legal fee for this work is money well spent and is likely to be money saved over a not-so-long run.

Although many lawyers are familiar with establishing profit-making corporations, the requirements for tax exemption are not commonly seen in the typical attorney's practice. Thus it is preferable to engage an attorney who has done some tax exempt incorporation before. If that experience is not available, then the lawyer chosen should be someone who is willing to work closely with the applicant coalition and is willing to spend the needed extra time in learning this somewhat specialized area.

The specific requirements for tax exemption are pursued through the United States Internal Revenue Service. IRS Publication 577, "How to Apply For and Retain Exempt Status for Your Organization," must be consulted. This publication, available free from the IRS, describes what must be followed in the incorporating papers which are filed in the applicant's state and with the Internal Revenue Service. Package 1023, "Application for Recognition of Exemption," should be acquired at the same time; this package is also available free of charge from the IRS.

Preparing the corporate papers, and filing with the state and Internal Revenue Service will take the attorney some time, but the process is not too complicated to learn. State laws will vary slightly; the federal tax exempt provisions apply nationally.

The key point in these papers is that the federal tax exempt language and purposes must be in the Articles of Organization. Inclusion in corporate bylaws will not be sufficient. Hence, considerable time and effort can be saved if the incorporation papers can be prepared simultaneously with the application for tax exempt status. It is possible -- and frequently happens -- for an organization to apply for and receive tax exempt status months or even years after incorporation. However, such delay can cause problems, including the sometimes complicated and time consuming process of amending the Articles of Incorporation and the bylaws. Certain activities during the intervening time can even jeopardize acquisition of tax exempt status -- lobbying, technical profits, for instance. Sometimes there must be involved negotiations with Internal Revenue in order to clear the record and receive tax exempt status.

BASIC DOCUMENTS AND STRUCTURE REQUIRED BY LAW

The three basic legal requirements for incorporation are as follows:

Articles - filed with state; slightly difficult to change; the public record.

Bylaws - filed publicly, but easier to change; more details of internal structure.

Board of Directors - governing body; useful, especially for longer range thinking and stability of organization.

All three of these legal requirements are interrelated, but each has its own key points and potential problems to be dealt with. Each requirement is discussed in detail in the following sections:

1. Articles of Organization

Most states issue forms to be used for Articles of Organization that are similar and relatively simple. They constitute written assurance that bylaws have been adopted and that corporate officers have been selected. In most states, three positions are required: a president, a treasurer, and a clerk (or secretary). In some states, one person can fill all offices and in others up to three persons may be required by law. The officers may also be directors.

The incorporators can adopt temporary bylaws and select persons who agree to serve as directors until permanent bylaws can be developed and adopted and directors can be chosen according to those bylaws.

In addition to certification of bylaws and directors, the Articles of Incorporation must also include a statement of the purpose of the corporation. For the center to be operated by a parent coalition, this statement of purpose is extremely important. It must embody the philosophy and goals of the organization and simultaneously meet the requirements for tax exempt status according to the rules of the Internal Revenue Service. This latter requirement makes the statement of purpose somewhat lengthier and more complicated than it otherwise would be. But, again, preparing it carefully at the beginning will save time and repetition of work later. This is one of the points where the services of an appropriate attorney will be most helpful, because, in order to satisfy the requirements of the IRS for tax exempt status, this section of the Articles of Organization will need to state the overall purpose and then further define the purpose(s), the means for achieving those purposes, procedures for corporate dissolution, etc. This statement must be written in the language and format required to meet the specifications for exemptions described in IRS Form 1023.

2. Bylaws

Bylaws are the agreed upon rules that specify how the organization will be run. They formalize decisions about purpose, structure, and operation. Statutes regarding bylaws are generally permissive and they are construed as being internally directory. They do, however, indicate desirable provisions with respect to internal regulations or management of the affairs of the corporation. Explanations concerning the legal aspects of corporate bylaws can be found by checking with the State Secretary for the state in which the center will operate.

Although bylaws are often viewed as a technical, red tape nuisance that get in the way of delivering the desired services, they really should be viewed in quite a different light. They constitute a formal mechanism that allow an organization to establish a set of rules that, if carefully prepared, will actually facilitate the operation of business. They should contain thoughtful decisions that will prevent needless controversy and will lay out a structure that reflects the philosophy and goals of the coalition.

Initial bylaws can be simple. However, most parent center directors recommended consulting a lawyer (ideally a member or friend of the organization) if bylaws are to be drafted with incorporation in mind. The following information is usually necessary:

- name
- purpose
- terms and conditions of membership, classes of membership
- affiliation and dues
- number, qualifications, powers, duties and tenure of directors
- procedure for filling vacancies on board of directors
- number of directors required for quorum
- titles, duties, qualifications for officers

- election procedures
- procedures for removal from office
- specific authorizations for bookkeeping and accounting
- date of regular annual meeting
- manner of calling and conducting meetings
- fiscal year
- procedures for inspection of records
- procedure for alteration or repeal of bylaws
- Roberts' Rules of Order, or other parliamentary rules

Many of these provisions are standard legal requirements which can be adapted from other bylaws. Others have presented the need for some thrashing out of concerns and problems that are unique to coalitions. Following is a discussion of some of the issues particularly relevant to such organizations:

1) Name

The first issue relates to identity. The organization obviously needs a name. It is sometimes difficult to make a choice; yet if the choice is made on the basis of clear criteria and it generates enthusiasm, the name will rapidly gain momentum and therefore credibility.

Legally, even though the organization is a non-profit one, it must include one of the following words: Limited (Ltd.), Incorporated (Inc.), or Corporation (Corp.). The name should be consistent with the organization's purposes. It cannot duplicate the name of any other corporation within the state.

There are several categories from which a name can be chosen. Descriptive names usually describe the activities or services provided. Familiar examples include: "Resource/Information Center," "Child Advocacy Service," or "Parent Education or Training Center." An obvious disadvantage of this type is that what starts out being an accurate description can soon become outdated. A descriptive name, by too narrowly limiting the scope of activities, can prevent the flexibility needed to adapt to changing political and social circumstances. For example, some centers that originally limited their activities to information and referral soon found themselves providing case advocacy in response to constituent needs. Other centers which began with a focus on individual advocacy discovered that training groups of parents would help them realize their goals more effectively. As they gradually shifted their emphasis towards activities to promote independence and self advocacy, their original name no longer suited their activities.

Another possibility is a name which reflects the location of the center. Consideration should be given to a name which accurately reflects the region served by the Center. The name of a city or county may be too narrow, restricting outreach activities into other areas. Foundations which had previously given awards to organizations serving a particular city or area now recognize the impact of adjacent communities and have begun to distribute their funds regionally.

Names also describe the structure of an organiztion. For example, "coalition," "council," and "federation" indicate an entity formed from a number of separate groups and connote a sense of continuity and strength. This type of name allows for a great deal of flexibility with respect to specific activities, although the major constituency or purpose will usually be part of the name, i.e. "Coordinating Council for Handicapped Children," "Federation for Children with Special Needs," "Coalition for Handicapped Citizens," etc. Possibilities abound for combinations of all these types. Below are other general criteria to consider in selecting a name:

- It should be easy to read.
- It should be easy to pronounce.
- It should be suitable for use if the organization expands into different activities.
- It should be timeless.
- It should relate to the activities of the organization.

2) Purpose

The work done on developing the group's philosophical assumptions will pave the way for this section.

In the bylaws, the purpose may be stated very simply, in everyday language. For example, the bylaws of the Coordinating Council for Handicapped Children in Chicago state that the purpose of that organization ". . . shall be to obtain better services for all handicapped children through advocacy, public education, referral, and special services." Others have found it practical to write this section in much greater detail, including all of the legal provisions in the Articles of Organization which will enable the coalition to conform to the federal laws on tax exemption. Although it is not necessary for these provisions to be written into the bylaws, it is excellent preparation for completing the information required in the Articles of Organization.

It is appropriate to request copies of bylaws from other organizations with similar objectives. Since state laws vary, it is useful to examine organizations within your own state. Federal requirements regarding tax status are applied nationally, so an out-of-state organization which has detailed bylaws, written explicitly to conform to federal laws, may also be helpful. (Volume II of Coalition Quarterly will contain sample bylaws and other model documents.)

3) Membership

The composition of membership will reflect the relationship of the organization to its constituency as well as the dominant values and attitudes of the organizers.

Three major options regarding membership in coalitions are available:

- membership is limited to organizations
- membership is limited to individual persons
- membership may be composed of some combination of organizations and individual persons

If the first option is chosen, a decision must be made regarding issues such as restricting membership to organizations whose primary membership is composed of parents of handicapped children. Will professionals be permitted? Under what conditions?

If individual members become the preferred choice, must they be parents? Professionals? If there is to be a combination of parents and professionals, what percentage of each is allowable?

There are several arguments favoring an exclusively parent organization. Recent national history has indicated that paid, professional staff generally outlasts parent volunteer efforts. They ultimately dominated organizations that once began as parent efforts; thus the original consumer emphasis and input were lost. Also, if parent leadership has evolved from a larger coalition representing a diverse perspective, there may be a need to create a forum which reflects solely the parent viewpoint.

There are several arguments on behalf of restricting membership to organizations only. Some centers feel that a policy admitting individual membership places them in competition with those groups that already existed to represent specific disabilities. By having entire organizations represented, the center will:

- prevent or reduce fragmentation;
- consolidate fiscal and manpower resources;
- add credibility by demonstrating that leadership can bring a variety of special interest groups together;
- have a greater public impact because of larger numbers;
- focus public awareness on common concerns among varied organizations.

One way of exercising this option has been to allow organizations as members of the coalition with the individuals belonging to each organization becoming individual members of the coalition.

If the group is to be comprised primarily of organizations, the choice becomes which parent groups. This choice becomes difficult in areas where parent groups proliferate. Some groups are large, some small; some are statewide, some are not. If every parent chapter or local group became a voting member, the Board of Directors could number in the hundreds. The question is really how to represent accurately the concerns of all parents, while having an organizational structure which can operate efficiently. By making provisions in the bylaws, it is possible to leave the issue of adding to and expanding the membership in the hands of the existing members and their Board of Directors. Such a provision allows flexibility and leaves some of the difficult questions open to further discussion.

If the group is to be composed primarily of organizations, there are some criteria for admission to membership to be considered:

- That the organization have a primary concern with children and/or consumers with special needs;
- That it have a constituency made up primarily of parents;
- That organizations of adults or other adult consumers' advocacy groups be granted membership (may be non-voting, or advisory only);
- The possibility of professional organizations that have consistently aligned themselves with parent advocacy efforts.

These questions can be considered by representatives from organizations which have expressed interest in joining the group.

Individual membership only, or a combination of individual and organizational membership may be necessary in areas where there are few parent organizations established. Some centers have found it practical to admit individual members as a means of raising some of their funds through dues. In this case there is generally a separate fee for organizations and for individuals.

4) Voting

Voting privileges will vary depending upon the type of membership chosen. Should individuals have voting power equal to that of an organization? The Federation, which has only organizations as members, allows each organization one vote. This decision was reached after lengthy discussion and careful thought about such topics as competition and relative power; the conclusion might well be different for other parent coalitions, depending on local needs.

5) Other Considerations for Bylaws

a) Involvement of Professionals

It may be important in the beginning to restrict membership to parents. However, once a certain strength is achieved and recognized, it may promote the cause more effectively to have concerned and aligned professionals involved, either as members of the board and ad hoc committees or as liaisons to assist with cooperation and alliances with professional organizations.

Although a healthy distance from professionals and professionalism is often appropriate, it is also important to avoid needlessly adversarial relationships. As a matter of fact, many centers are now conducting training in parent/professional relationships, with both parents and professionals conducting and receiving the training.

b) Independence or Autonomy of Members

Parent leaders interviewed have found that specific organizations may have particular issues about which they feel strongly, and may disagree with other members. Such disagreement is an especially sensitive issue when a coalition issues public statements.

A procedure can be adopted in the bylaws that would allow representatives of member organizations to dissociate themselves from any activity or position of the coalition or organization that is not acceptable to its constituency, simply by so stating. Since much of a coalition's strength derives from its consensus and unity, such a procedure creates room for disagreement without having to break off membership. Attempting to coerce agreement defeats that underpinning. Faced with strongly held disagreement, coalitions might decide not to pursue the issue at all -- or at least, to make very explicit the fact that, on this issue, only the agencies are in agreement.

3. Board of Directors

As indicated above, a board of directors is legally required for incorporation purposes and serves as the governing body of the organization. The directors determine the policy and general direction of the activities of the corporation.

The founding members must determine the criteria for directorship and the process and rules for election. These will reflect some of the same issues encountered regarding admission to membership. Possibilities for selection to the board may include: parents only; no such requirement of any kind; that the issue be left to each participating organization.

The Board of Directors should be a critical resource for the organization and under no circumstances should they be dismissed as perfunctory. Careful consideration should be given to the selection of directors because of

the perspective they can bring to the overall activities of the organization.

They are also important liaison persons bringing credibility to fundraising activities and broadening the community based network.

BIBLIOGRAPHY

Des Jardins, Charlotte, How to Organize an Effective Parent/Advocacy Group and Move Bureaucracies, published by Coordinating Council for Handicapped Children, 407 S. Dearborn, Chicago Illinois 60605.

"Federation for Children with Special Needs: An Overview," free Information Sheet developed by Federation for Children with Special Needs, 120 Boylston Street, Suite 338, Boston, Massachusetts 02116.

Focus on Special Education Legal Practices: A Quarterly Information Sheet Providing Specialized Commentary for Organizations Serving Handicapped People, Editor, David C. Trott, Esq., Published and Distributed by Closer Look, Box 1492, Washington, D.C. 20013. (Vol. I, No. 3 deals with lobbying and tax-exempt status.)

"Handbook for Planning and Organizing Advisory Councils for Special Education," prepared by Parent Training Group, Special Education Manpower Project, Massachusetts Dissemination Project, Massachusetts Department of Education, Room 614, 31 St. James Avenue, Boston, Massachusetts 02116.

"How to Build a Coalition of Parents of Handicapped Children," free Information Sheet published by PACER, 4701 Chicago Avenue South, Minneapolis, Minnesota 55407.

"Organizing a Parent Group," Task Force on Education for the Handicapped, 812 E. Jefferson Blvd., South Bend, Indiana 46617.

"Starting a Parent Center," Southwestern Ohio Coalition for Handicapped Children Parent Information Center, 3024 Burnet Avenue, Cincinnati, Ohio 45219. Available at cost.

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ADVOCACY MANAGEMENT IN THE PARENT CENTER

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INTRODUCTION

A basic commitment to advocacy underlies nearly all the activities undertaken by centers operated by parent coalitions. This commitment is central in the history of the centers, since most are staffed by parents who became involved in coalition building and related activities as part of their own voluntary efforts as advocates. The previous issue of **Coalition Quarterly** (Vol. I, Numbers 2 and 3) dealt with some common philosophical assumptions shared by parent centers and the way these are built into the organizational structures. This issue discusses in detail the application of philosophy in the form of advocacy and the relationship of advocacy to the management of a center. Because advocacy is so important both to the philosophy and to the operation of the centers, it will be dealt with in greater length than originally planned; thus this issue has been developed as a double issue, Numbers 4 and 5 together.

Broadly defined, advocacy means to act on behalf of another to promote that person's causes as if they were one's own. Most important, advocacy requires placing the interests of the client above other considerations. For this issue of **Coalition Quarterly**, we have adopted the Kahn, Kamerman and McGowan division of child advocacy into two separate but related areas: case (one-to-one) advocacy and class, or systems advocacy.[1] We will emphasize the relationship between the two types of advocacy as seen in the operation of parent centers.

PART 1: CASE ADVOCACY

The first article, CASE ADVOCACY IN THE PARENT CENTER, focuses on the management problems that arise from a total commitment to case advocacy. Within the context of this discussion, case advocacy means one trained parent helping another parent to acquire services for his/her handicapped child. The need for case advocacy was especially compelling when P.L. 94-142 and similar state special education laws were first being implemented because parents were faced with a whole new array of procedures and responsibilities for which they felt ill-equipped. Consequently, they sought assistance from other, more experienced parents for help in developing these new skills.

Since most parent centers begin with case advocacy, a thorough understanding of both the benefits and problems accompanying this activity is crucial for developing preventive strategies for newcomers and redmedies for more experienced centers.

At the core of the problems is a paradox. On one hand, the basic motivating force behind creating the organization is a strongly-felt personal commitment to help families. Yet, unless activities are carefully managed, there is a danger of dampening the initial impulse by caseloads which can quickly become overwhelming. Also, as parent organizations grow, their ability to effect change is no longer limited to individual cases and they often become involved in system advocacy. However, a total switch to system advocacy may fail to provide the strong personal gratification and inspiration that helping individual children does. This article outlines possible problems, offers some solutions, and gives a rationale for a continuing involvement in case advocacy.

Following the discussion of case advocacy is an article entitled PARENT TRAINING: A STRATEGY FOR SOLVING THE PROBLEMS POSED BY CASE ADVOCACY. In an effort to solve some of the problems involved in an exclusive commitment to individual case advocacy, various parent centers over the past five years have been developing workshops or training sessions to supply groups of parents with the knowledge and skills they need to become confident advocates for their own children. Group centered training allows the center to reach many more parents and often serves as the foundation for parent-to-parent support systems, thus reducing the need for direct staff involvement in individual cases. By empowering parents to act on their own behalf, as well as for others, another danger, that of creating a dependency system, is avoided.

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[1] Kahn, A.J., Kamerman, S.B. and McGowan, B.G. **Child Advocacy: Report of a national baseline study**, (DHEW Publication No. OCD 73-18). U.S. Government Printing Office, Washington, D.C., 1973.

PART 2: SYSTEM ADVOCACY

The remaining articles focus primarily on the role and legal implications of class and system advocacy in the parent center. Involvement in system-wide advocacy is an obvious, powerful way to expand the resources of the advocacy organization. The aim of system advocacy is to bring about changes in institutions, agencies and services so that groups of people are beneficially affected. This type of advocacy includes influencing legislation, systems analysis to identify service needs, community organization, and litigation in order to effect changes in existing mandates, policies and procedures.

In most centers, system advocacy evolves naturally from case advocacy as staff workers learn to use their experiences and documentation of cases to identify system-wide problems. Once the process of effecting change on this broader level begins, there is still a need to have continued contact with the kind of information that originally prompted advocacy efforts for parent centers, this means an ongoing involvement with individual case advocacy. Elizabeth Britten, director of the Southwestern Ohio Parent Information Center, pinpoints some of the difficulties involved in a transition to system advocacy:

- It is difficult to tell a fellow parent that there is no help with their specific case because all energies are committed to making a change in an issue which may not make a difference for that parent seeking immediate relief.
- New skills may need to be learned, especially in the areas of policy-making, litigation and lobbying.
- There may be restrictions in the parent center's funding contract or in the coalition's tax exempt status.

She concludes that system advocacy is the long-range solution to major problems shared by many parents of handicapped children, and that effective changes occur when both case and system advocacy are exercised concurrently — a difficult task which requires careful planning.[2]

Litigation is one form of system advocacy highlighted in an article by Lawrence Kotin, Esq., LITIGATION AS AN ADVOCACY TOOL. He discusses the role a center can play in using the courts, describes the legal process, and reviews some of the relevant cases which have been decided during the past several years.

Robert Crabtree, Esq., addresses the management issues related to Internal Revenue restrictions on political activities or lobbying in the final article, POLITICAL ACTIVITIES AND THE IRS.

In order to tap a wide base of experience and knowledge for these complicated problems, we have invited several specialists to contribute articles or background information for this issue of **Coalition Quarterly**.

CASE ADVOCACY IN THE PARENT CENTER

Purpose

One-to-one advocacy as practiced in parent centers is a very specialized form of peer support — staff members, because they are themselves parents of handicapped children, relate on an equal basis to the parent who comes to them for information and assistance. Advocacy is distinguished from other forms of peer help by its focus and its intention. Although the built-in empathy or rapport characteristic of parents helping parents is a tremendous source of moral and emotional support, the focus of the advocacy practiced in parent centers is not primarily on the emotional needs of the clients. Unlike psychological counseling, the intention here is to provide the necessary information and support a parent may need to obtain the services which will enable the family not just to cope but to prevail.

[2] Britten, Elizabeth, "Starting a Parent Center," Southwestern Ohio Coalition for Handicapped Children Parent Information Center, 3024 Burnet Avenue, Cincinnati, Ohio 45219.

The ultimate purpose of a parent center is to insure that the rights and interests of disabled persons will be protected. Although the questions that parents raise relate to many areas — financial entitlements, medical needs, respite care, recreational opportunities, etc. — the overriding expectation of parents seeking help from a parent center is the hope that an appropriate educational placement will be assured for their child. Frequently, achieving this goal requires direct, one-to-one assistance.

Description

This advocacy activity can be described as a continuum. Occasionally a parent will call with a simple question requiring a simple factual answer ("Is my four-year-old deaf son eligible for special education?"). In most cases, however, one question leads to another, revealing new areas of uncertainty ("Does this eligibility include hearing aids? Transportation?"). An advocate's involvement will gradually increase from providing factual information, to assisting in the interpretation of a child's records and advising the parent on the proper procedural steps to take, to accompanying the parent to official school meetings. Finally, the advocate may act in a paralegal role and actually represent the parent in a formal administrative hearing. This transition from simple and quick to complex and time-consuming often places a far greater demand upon staff and volunteer networks than can easily be met.

PROBLEMS

Case advocacy is both a major strength and a potential danger for parent centers. Ironically, it is the organization's success that is the source of many of the dangers. For example, in most cases, because staff members are themselves parents of handicapped children, they have a great willingness to respond thoroughly to the needs of other parents, often at some personal cost. Consequently, the parents who call, often after many frustrating attempts to obtain help or information elsewhere, are pleased with the quality of assistance they receive. As parent centers become known as a source of this type of assistance, they are often deluged with more requests from parents; also, an established reputation for "never giving up" makes the center the prime focus for referrals from other agencies for their most difficult cases.

This increased demand saps more and more of the limited resources of the center. Also, since staff members are so strongly committed, they find it difficult to limit the demands made on their time and can very readily overextend themselves. Thus, an activity which offers great satisfaction quickly becomes overwhelming, leading to frustration and burnout.

The problems associated with case advocacy are at the heart of most management concerns for parent centers and they arise repeatedly, although with a different slant, in every area of office functioning — staff management, funding, hiring practices, even office layout. Basically the problems fall into the following areas:

1. Philosophically, there is a danger of creating a new dependency system rather than encouraging parents to develop and respect their own resources as parents.
2. Two major dangers go hand-in-hand with success:
   - — Once an advocacy organization becomes known and respected it will often receive more requests than can be handled adequately; and
   - — The successful organization becomes the focus for the most difficult cases. In other words, the better the staff members do their work, the more difficult their work becomes.
3. Since parent staff members are so strongly motivated, they are more vulnerable than others to the problem of burnout.
4. In the traditional ways of accounting, it is not cost effective to provide this kind of service on a one-to-one basis, especially if that is the only or primary function of the staff.

In addition to the problems listed above, funding for individual case advocacy is almost non-existent.

Long-Range Solutions

One long-range solution to these problems is to provide parents with the opportunity to gain the skills and information they need to advocate effectively for their own children. Parent training designed to meet such a goal is discussed in detail in the following article. This training serves not only to empower parents and increase their independence, but it also expands the organization's effectiveness; groups of parents receive information together rather than individually, and many parents are willing and able to help others as volunteers.

The use of various forms of issue advocacy and the development of written materials, such as fact sheets on relevant laws, information bulletins on current legislation, lists of resources, etc., also increase the center's ability to reach more parents, thus increasing cost effectiveness.

Finally, involvement in such a variety of activities provides a newness which helps staff members avoid burnout.

BENEFITS

There are many reasons for centers to maintain a continuing involvement in individual case advocacy, in spite of the difficulties outlined earlier. The following is a brief summary of the major advantages:

1. In order to supply parents with relevant information that will enable them to advocate on behalf of their own children, it is vital that trainers possess specific and current information about the problems parents are confronting. The development of appropriate written materials and, most particularly, the successful application of issue advocacy are dependent upon the information gained from direct individual case involvement on a continuing basis.

2. Although there are dilemmas that are inherent in a strong personal commitment to young children and families, staff members find working on a personal basis with families most appealing. It satisfies their desire to help in a most basic and tangible way. It is children, the primary force behind the commitment, who provide the rewards When an individual child is helped, the gratification is immediate and powerful. Systems advocacy, on the other hand, may take years to reach its goal and a person may never directly experience the results of her endeavors with the immediacy that individual case advocacy provides.[3]

3. There will always be instances when parents need one-to-one assistance. People with needs will call; often these are the most compelling calls. They carry a message of urgency which can be an important force in creating change. Furthermore, they supply staff members with daily reminders of the relevance and urgency of their work.

4. On a broader scale, an involvement with case advocacy provides the collective documentation necessary to determine where and when systems need change. Transportation to and from school is an obvious example of a system-wide problem in many areas of the country. In order to effect changes, documentation must indicate the exact nature and scope of the problem. One parent center's involvement with transportation problems is described in the article on system advocacy.

5. Through their efforts with individual cases, the parent centers establish credibility among parents and establish a reputation as an organization representing a parent consituency, thus strengthening the supports needed for successful involvement in class and system advocacy.

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[3] Britten, Elizabeth, "Starting a Parent Center".

MANAGEMENT SOLUTIONS

As in any organization, a careful overall balance must be maintained between dealing with crises, usually on an individual basis (reactive), and long-range planning, which includes system advocacy and parent training (proactive). There are many ways to achieve a balance. Every center has its own focus and reaches its own equilibrium depending upon the needs of its constituents, the social and political climate, funding requirements, and the talents and abilities of its staff. Organizational equilibrium is an evolving and ever-changing process. The fact that an organization changes is an indication that it is in touch with and responsive to its overall goals, rather than simply working for its own status quo.

Experienced parent centers have offered the following suggestions to consider before case advocacy becomes overwhelming:

— Determine the number of cases that can be handled, both by individual workers and by the center as a whole.

— Limit case load by employing alternative ways to meet the needs of parents.

— Consider taking only certain types of cases for one-to-one involvement — those requiring due process, for example.

— Refer cases to other advocacy groups which may specialize in a given area.

— Work closely with other advocacy organizations to avoid duplication and to enhance possibilities for cooperation.

— Conduct training programs for parents in self-advocacy.

— Develop handout sheets of resources and fact sheets on various rights: for example, listings of parent disability groups and procedural steps in due process.

— Encourage staff members to serve on relevant boards and committees and to attend agency meetings as a means of participating in policy-making decisions.

— Provide back-up support that staff members need to balance the highly emotional nature of their involvement; i.e., set a time for staff members to sit back and talk, conduct inservice training for stress management, schedule regular case conferences.

— Include staff in long-range planning to determine which problems should be considered for system advocacy.

— Conduct staff training in system advocacy, its goals, strategies and value.

— Train staff and volunteers to see case advocacy as an ongoing monitoring and needs assessment opportunity that may lead to class or system advocacy.

— Train and empower local parent groups.

— Develop and utilize volunteer capacity, including other parents, students, and retired persons.

— Publish a newsletter.

Forthcoming issues of **Coalition Quarterly** will expand upon the items listed above. These are suggestions for coping with the problems outlined earlier and are not intended to be a comprehensive survey of all the strategies used to solve them.

PARENT TRAINING: A STRATEGY FOR SOLVING THE PROBLEMS POSED BY CASE ADVOCACY

by Mary O'Brien, Training Coordinator, Massachusetts
Federation for Children with Special Needs

Need

People associated with the centers operated by coalitions around the country have become increasingly aware that many of the parents of handicapped children to whom they were providing information and other assistance did not really comprehend the rights and protections afforded them and their children under state and federal laws. Often, lack of understanding by the parents left the children vulnerable to grave abuse (exclusion from school, continued school failure, unnecessary segregation from their peers, for example). By the time these cases came to the attention of parent center workers, the problems had reached critical stages — parents felt guilty, helpless, angry, and immobilized. Staff members were faced with providing emotional support in addition to finding a way to help the parent secure an appropriate program for the child.

Goals

Several centers decided to develop parent training that would empower parents to act early for their own children and thus be able to prevent the crisis stage. Two general goals were developed for the workshops:

1. To provide technical information and to develop skills which would enable parents and providers to access the services guaranteed by law to children with special needs, thereby developing a network of support in the community for these children.

2. To clarify the role of the parent in the child's educational planning process.

STRATEGIES AND CURRICULA

Exchange of curricula and materials among the parent centers and other agencies has enhanced the quality of this training. At the Federation, for example, after a review of materials developed for a variety of projects that had training components, we planned a curriculum based on the four rights guaranteed under the special education laws and the two key protections that ensure these rights. (This format had been used successfully by the PAVE Project at Closer Look and earlier by TASK, a parent coalition in Orange County, California.) The steps from referral to the writing of the IEP provide the content of all training workshops, whether they are set up as a series or are presented as a single session. All of the written materials we now use can be adapted for these two structures.

People who attend the workshops come from a variety of socio-economic and racial groups. We have learned that while the levels of sophistication, privilege and expectation of parents vary widely, they share a common problem. Typically, parents do not view themselves and are not viewed by professionals as colleagues on the Team. Since the intent of the law includes parents as colleagues on the Team and not as clients, or patients, we have developed a strategy for "professionalizing" parents.*

The PACER Center in Minneapolis, one of the first parent centers to adopt training as a major strategy, achieves this same aim of "professionalizing" parents of handicapped children by offering workshops at three levels. The first level is parent education. At these meetings, parents learn about their rights and responsibilities in special education, their role in helping to develop their child's individual education, parent/school communication, and the basics of advocacy. The second, more specialized, level of training focuses on such particular areas as preschool special education needs and services for children in segregated schools. The third level is advocacy training, which includes detailed information on various aspects of special education laws, assertiveness techniques, and other ways of assisting parents to help other parents.

* Editor's Note: To help strengthen advocacy efforts, some centers provide parallel training to medical professionals and other members of service delivery systems to sensitize them to parents' issues.

Recently, the major strategy employed by the Federation has been a Parent Manual which is used as a training device for promoting self-advocacy. The manual is a carefully designed and piloted notebook that contains basic information for all parents and separate sections for information relevant to the particular child. The notebook enables the Federation staff to adapt the curriculum to any audience or format and can be compiled with participants during a single workshop or a series of workshops. The notebook is the product of a process in which the parent has participated. Parents have found it to be particularly helpful in organizing their children's records, having ready access to technical information about laws while they participate in planning for their child's education with other members of the educational team.

SUMMARY

In each center, the training provided parents has also enhanced the group's effectiveness in assisting the parents on a long-term basis; parents who have attended the workshops call back for follow-up information, but are often able to handle their own cases effectively. Their questions are informed and specific. The case files they compile for their children are complete and they provide clear documentation of their children's needs. This documentation often prevents the need for mediation and/or a formal due process hearing, and it facilitates the development of an appropriate IEP.

At the Federation, we have discovered that engaging in training has helped our staff to mature; they have come to realize that their pioneer years of experience and struggle have provided them with invaluable knowledge, strength, and confidence. They have learned that the best way to help other parents grow is to give them clear information, new skills, and the belief that they are entitled to services for their children.

Staff members have concluded that the way in which a request for information or assistance is handled can make parents feel either dependent or empowered. Thus, every inquiry becomes an opportunity for training: by mailing material as follow-up to a phone call; by helping a parent arrange records carefully in the notebook; by urging parents to assist and learn from one another, returning to the center whenever there is a need for more information.

Most other centers we have talked with have developed the same dual emphasis that we have outlined: increasing parents' knowledge of the laws, and enhancing their confidence as colleagues on the educational team. The New Hampshire Parent Information Center focuses curriculum on specific topics, such as "Play and Leisure Activities" and "Behavior Management Techniques" in addition to workshops on basic legal rights and due process. For many years, the Coordinating Council for Handicapped Children in Chicago has conducted parent training workshops that emphasize independence and strength for parents, based on sound knowledge of the law and acquisition of assertiveness skills.

CLASS OR SYSTEM ADVOCACY

Along with training parents to become advocates for their own children, the other, obvious solution to the problems of case advocacy is to engage in class advocacy, to effect change that will benefit large numbers of children. Like case advocacy, class (or system) advocacy is also an important part of the history of coalitions of parents of handicapped children. Most parent coalitions emerged from an organized effort to achieve major changes in services for handicapped children, usually in the form of special education laws at the state and federal levels.

Management Issues

System advocacy poses its own set of management challenges for the parent center. Again, because the center's workers are themselves parents of children with special needs, they are likely to share personally the frustrations of their clients, either in the past or even concurrently with the parents they are helping. Thus the urgency of each crisis creates overwhelming demands for action.

Like case advocacy, class issues must be identified, sorted, and selected for action by the center according to the organization's capacity to handle them. Frequently, there is another agency with greater capacity to deal with a particular problem, and that ageancy should be given encouragement and support from the parent center. The state's Developmental Disabilities Protection and Advocacy System may be the best qualified organization to take the city's mass transportation system to court for discrimination against handicapped persons; the state Association for Retarded Citizens may be the logical group to tackle zoning laws that are designed to exclude community residences for handicapped people; the parent center may be the appropriate agency to solve problems with the state education department's implementation of the surrogate parent requirement of the federal special education law.

Effective class advocacy often requires access to attorneys who specialize in relevant laws. Although their role in the area of litigation is obvious, attorneys are also needed in other less adversarial roles, such as helping to make the decision whether or not to pursue litigation; drafting legislation if that is the chosen strategy; and interpreting laws, regulations, and judicial decisions. Furthermore, attorneys experienced in litigation can be invaluable advisors in defining the issues and developing the arguments, no matter what mode of persuasion or pressure may be adopted. Finally, attorneys can share with parents their training and experience in mediation when that promises to be a possible solution.

Since most parent centers cannot afford the luxury of paid staff attorneys, they must find alternative legal resources. Some centers have a board member who is both an attorney and a parent of a disabled child and is available for a certain amount of free legal assistance. Other centers have developed cooperative relationships with attorneys in other agencies, including public interest law firms and other child advocacy organizations.

Because the needs for class advocacy are likely to be even less predictable than are the needs of individual parents, the center almost inevitably finds itself in a reactive stance rather than a pro-active position based on careful planning. The center becomes so busy responding to each successive crisis that it neglects to do the planning that can produce an effective concerted advocacy effort. However, planning can be facilitated with only a little extra effort, especially if the workers can be persuaded to view all their work within a context of system advocacy in the following ways:

1. Document the inquiries coming into the center in such a way that the task of identifying and verifying systemwide problems will be facilitated.

2. In addition to the intake forms that are used for telephone calls, questions that are raised in training workshops, conferences, informal meetings, or any other context should be recorded, preferably on a standardized form.

3. Regular staff meetings and board meetings should include an agenda item devoted to case conferences or reports on problems being expressed by parents of handicapped children, and these also can be recorded on the standard form.

4. A process should be developed for making decisions about which issues the center will choose to take on as class advocacy efforts. The decision process should include both workers and board members.

Considerations for Selecting Strategy

Once a decision has been reached to pursue a particular class issue, then a strategy (or series of strategies) must be selected for accomplishing the goal: litigation, legislation, a quiet telephone call to a key official, a mass demonstration, press campaign, a few key letters, a mass letter-writing campaign.

One helpful principle in this selection process requires that the strategy chosen should be the one that is least complicated, least time consuming, and likeliest to solve the problem at the earliest possible stage. A common example would be to train parents to solve the problem (specialized transportation, for instance) at the IEP planning meeting to avoid a long and costly due process experience.

In addition, the following considerations will help determine the best option:

1. Current legal status of the issue. (For instance, is the problem one of noncompliance with existing law, one needing new legislation, or one requiring interpretation of present law?)
2. The remedy that holds most promise for solving the problem. (Example: Should the outcome be to improve evaluation methods in order to increase the accuracy of classification of children? Or, should the result be the elimination of labels that are ambiguous and stigmatizing?)
3. Those components in the overall system best equipped to act to resolve the problem. (Well organized, active parent groups? a sympathetic judge? a helpful legislative leader? a responsive state administrator?)
4. The future effect of approaches used in the present. (Would a one-time media expose jeopardize cooperation in the future? Would certain kinds of activities and not other kinds endanger the center's funding source? Would too much compromise sacrifice the support of the coalition in the larger effort?)

Example

The following example will illustrate the application of the above determinations to an issue that has presented problems almost everywhere in the country: the transportation of children with special needs to and from school. Since transporation is a mandated service, change was not needed in law or policy, but rather efforts were needed to force compliance with the law.

A few years ago, when school opened in September, the Federation for Children with Special Needs received numerous complaints and requests for assistance from Boston parents about the conditions under which their handicapped children were being transported. The complaints were serious; the safety of the children was being ignored; large numbers were not receiving the transportation required in their education plans. Many children were not picked for weeks at a time; others were hours late when they finally arrived at school only to be returned home to frantic, worried parents hours after school was over. One child, unable to walk, was left alone on a sidewalk in front of a housing project. It became obvious that the critical need of Boston children in special education at the time was safe and efficient transportation.

Because of the magnitude of the problem in sheer numbers of unserved children, it was obvious that handling each case individually was impossible. In addition, after attempting to secure adequate services for individual children, it also became obvious that there was no person, department or agency within the public school system equipped to take responsibility for guaranteeing safe, prompt, and reliable transportation. The school department had provided only one telephone number to register complaints and that number was either busy or nonfunctional. Therefore, the advocacy strategy assumed from the outset was adversarial, since the mechanisms for mediation and cooperation were non-existent.

As a community effort to remedy the situation, Boston parents formed the Committee to Get Our Kids to School. The Federation served as a support for the parents involved by setting up a hot-line, publicized through the media, to respond to and document complaints about transportation. When one hot-line proved to be inadequate, another state advocacy organization, Office for Children, set up a second line. In a three-month period over 3,000 unduplicated complaints were logged by the two agencies.

Careful records detailing all the pertinent information were kept and forwarded, at the end of each day, to the Transportation Department of the Boston Public Schools and to the state Department of Education. Copies of each complaint, filed with both organizations, were kept at the Federation.

Since neither the Federation, the Office for Children, nor the ad hoc committee had the capacity to file suit, the documentation was turned over to another child advocacy agency, the Massachusetts Advocacy Center, which had on staff an attorney specializing in litigation. The attorney then used the information

collected as the basis for affidavits which were used in a class action suit against the Boston School Department. The suit succeeded in forcing the contracted private bus firm to adhere to the terms of their contract, thus forcing all parties to comply with the law requiring safe and prompt transportation.

Far from creating future hostility among Boston special educators, the careful process that was put in place allowed teachers and school administrators to call the hot-line and help get the problem resolved.

LITIGATION AS AN ADVOCACY TOOL

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How Courts Become Involved

The courts are an advocacy tool of last resort "when all else fails." There are two ways in which the courts become involved in resolving "class" or "system" issues under P.L. 94-142, i.e., those issues which affect large numbers of children and some major part of the service delivery system. The first is through an appeal from the state "due process" administrative system, e.g., from a final decision of a hearing officer or a state superintendent of education to a state or federal court, at the option of the party appealing. The second is through a direct action brought in state or federal court, without a preceding administrative process.

In both instances, the case begins in the lowest court of "general jurisdiction" which, in the case of state courts, is the main trial court (which has different names in different states, such as "superior court," "supreme court," "supreme bench," etc.) and, in the case of the federal courts, is the federal district court (unlike the state courts, this is uniform throughout the country). After this court (state or federal) issues its decision, subsequent appeals are possible, in the case of the states, to the highest court of the state, usually through an intermediate appellate court and, in the case of the federal courts, to the federal court of appeals for the circuit in which the district court is located. Ultimately, both state and federal appeals can be appealed further to the United States Supreme Court, which has the discretion to accept or refuse to accept the case.

Appeals which arise from the state administrative process are, most commonly, those which raise the issue of the "appropriateness" of a child's placement. "Class" or "systemic" issues are raised through these appeals when a significant question of law must be decided in order for the issue of appropriateness of the placement to be resolved. For example, an issue which commonly arises through the administrative appeals process is relative agency responsibility for a child's placement, e.g., mental health, education, social services, etc. This question in turn requires a definition of what is "special education" and "related services" and what is not.

Cases which go directly to court without a preceding administrative process generally raise issues which do not lend themselves to decision through the normal administrative process for the following reasons:

(1) the issue is too urgent to wait for the appeals process to run its course, such as in the case of an expulsion of a handicapped child from school for disciplinary reasons;

(2) the issue requires a resolution which is beyond the normal authority of a hearing officer, such as non-compliance by a local educational agency with one or more major provisions of the law; or,

(3) the magnitude of the issue requires resolution by a higher authority, i.e., a court, such as an issue relating to retroactive payment to parents of private school costs where the parents ultimately win their case on appeal.

Types of Issues Resolved in Court

To illustrate the kinds of "class" or "system" issues which tend to get resolved in court either through an appeal from an administrative decision or through a direct court action, we will review some of the cases which have been decided during the past several years. Overall, there have been at least four categories of these cases, most of which have gone directly to court without a preceding administrative process:

(1) major enforcement cases, each raising a number of basic issues of implementation of significance to large numbers of children;

(2) cases challenging the suspension and expulsion of handicapped children from public school;

(3) cases raising various issues relating to private school placements; and,

(4) cases involving the interpretation of specific provisions and requirements of P.L. 94-142 and its regulations.

The major enforcement cases challenge the widespread and substantial failure of a state to implement one or more major provisions of P.L. 94-142 or its state analogue. An example of such a case is **Allen v. McDonough**, a case filed against the Boston School System for its failure, on a timely basis, to conduct evaluations and reviews and to make placements. Other prominent examples are **Mattie T. v. Holladay** in Mississippi and **California Association for the Retarded v. Wilson Riles**.

These major enforcement cases are very much akin to the landmark "right to education cases" such as **PARC, Mills and Lebanks v. Spears**, which preceded P.L. 94-142 and were a major impetus to its enactment. The principal difference between the two lines of cases is that the pre-94-142 cases were based on the provisions of the United States Constitution, while the enforcement cases are based primarily on the mandate of P.L. 94-142, itself. (It should be noted that although some of the enforcement cases were filed before P.L. 94-142 became effective and were then based primarily on constitutional or state law provisions, they now rely on P.L. 94-142 as their primary authority.)

Several major cases have challenged the use of disciplinary suspension and expulsion against handicapped students. Examples of these are **Stuart v. Nappi** in Connecticut, and **Howard S. v. Friendswood Independent School District** in Texas. The issue raised in these cases is the extent to which special education requirements have replaced the use of suspension and expulsions in the case of handicapped children. In the Connecticut case, for example, the court ruled that suspension of a handicapped child was a "change in placement" under P.L. 94-142 and required the application of special education "due process procedures."

A third category of "class" or "system" cases are those deciding issues relating to private school placements. Examples of these are cases in Illinois (**Elliot v. Board of Education of the City of Chicago, Illinois**) and Florida (**Scavella v. The School Board of Dade County, et al**) which address the issue of a cap on public funding of private tuition; cases in Connecticut (**Michael P. v. Mahoney**) and Florida (**Jenkins v. State of Florida**) in which challenges were made to a system of charging parents for certain costs of institutional placements; a case in Massachusetts (**Amherst-Pelham Regional School Committee v. Department of Education**) deciding the issue of retroactive payments to parents who place their children in a private school at their own expense and then win their case on appeal; and cases in the District of Columbia (**North v. District of Columbia Board of Education**) and Rhode Island (**Ruble v. Bevilaqua**) relating to relative state and local agency responsibility for public and private "institutional placements."

A fourth category of cases are those interpreting specific provisions of P.L. 94-142. One case in Pennsylvania (**Armstrong v. Kline**), for example, decided that an "appropriate placement" included a 12 month year when necessary. Another case in Connecticut (**Campochiaro v. Califano**) held that local school board members did not qualify as "impartial hearing officers" within the meaning of P.L. 94-142.

Role of the Center

There are several roles which a center can play in using the courts as an advocacy tool. One is to identify "class" or "system" issues and to suggest court action in the form of an individual complaint or a class action. Another is to help a party or a class secure legal assistance in bringing an individual or class action. A third is to file a brief in a case as an "**amicus curiae**" or "a friend of the court." **Amicus curiae** briefs are frequently filed in important cases by an organization which is very interested (by virtue of its work) in the outcome of the case. These briefs are frequently very influential in part because they can contain certain information about the non-legal implications of a case which is generally considered beyond the scope of the main briefs filed by the parties. As a procedural matter, a request must generally be made to the court for permission to file an **amicus** brief. Permission is generally granted to an organization which can demonstrate an obvious interest in the case as the result of its purpose and membership.

Summary

One further word should be added about the use of court litigation as an advocacy tool. In general, very few cases which are filed ever result in a final decision by a court. This is because the vast majority are "settled", i.e., resolved informally between the parties. This fact highlights a key purpose of using litigation which is to try to bring about a settlement by the suggestion or actual initiation of a court proceeding when all other efforts fail. Thus, litigation can be an effective tool for bringing about the informal resolution of disputes which have not been amenable to negotiations.

POLITICAL ACTIVITIES AND THE IRS

by Robert K. Crabtree, Esq., Kotin & Crabtree,
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Families of handicapped people have been among the most politically active citizens in the last two decades. The reason for this is simple — legislation and government policies and programs form the foundation of any entitlements handicapped persons can claim, and without organized persuasion of law and policy-makers, that foundation will erode. Since most Parent Centers choose to be not-for-profit organizations for the tax benefits that attend that status, and since the Internal Revenue Service (most states too) imposes certain restrictions on political activity, centers need to know how much and what kinds of lobbying they can engage in without jeopardizing their tax exemption.

The Internal Revenue Code ("IRC") provision that confers tax exempt status on some organizations [Section 501 (c) (3)] requires that "no substantial part of the activities" of the organization be "carrying on propoganda, or otherwise attempting to influence legislation" and that the organization "not participate in . . . any political campaign on behalf of any candidate for public office." There are now two tests which might be applied to your center to see if it has engaged in too much lobbying: (1) The old "substantial activity" test and (2) The "new test", a much more flexible standard which has been available since the enactment of the Federal Tax Reform Act in 1976 (IRC, Section 4911). You must affirmatively elect to be covered by the new test; otherwise, your political activity will be judged by the substantial activity test. Generally speaking, under either test, activities which are not prohibited to tax exempt organizations include: (1) Making non-partisan research or analysis available which presents information on both sides of a controversy; (2) Providing technical advice or assistance to a governmental body in response to a written request in its name (a request in the name of an individual member will not qualify); (3) Examination and discussion of broad social and economic problems even if they are the subject of legislative activity so long as the merits of a specific legislative proposal are not addressed. The two possible tests are as follows:

The Old Test

The "substantial activity" test denies tax exempt status to an organization for which lobbying is a substantial part of its activities. This test has created a great amount of uncertainty for not-for-profit organizations over the years. The test has proven to be unclear about what types of activity are prohibited and how much of that prohibited activity is "substantial." Moreover, the penalty for lobbying a "substantial" amount is an absolute loss of tax exempt status. Once the 501 (c) (3) status is lost, furthermore, an organization is ineligible for status as a "social welfare" organization [Section 501 (c) (4)]. [Under Section 501 (c) (4) a tax-exempt organization could lobby without limitation but gifts made to it would not qualify as tax-deductible contributions for the donors.]

Under the old test, the I.R.S. considers several factors to decide whether an organization has exceeded a permissible level of lobbying activity. For example: (1) Are legislators contacted directly or does the organization limit itself to testifying at hearings? (2) Is testimony volunteered or invited by the legislature committee? (3) How much time and money are spent in the lobbying activity? On the basis of these and other considerations, the I.R.S. found the Sierra Club's legislative activities to constitute a regular part of its functions and not a casual concern. As a result, the Sierra Club lost its tax exempt status under the substantial activity standard.

The New Test

You will only be covered under this standard if you affirmatively elect to do so by filing the appropriate IRS forms. If you are engaged in lobbying to any significant degree it is probably to your advantage to do so. The new test sets forth clear guidelines which permit substantial amounts of political and lobbying activity and imposes less harsh penalties for exceeding the limits. One disadvantage is that the new standard requires annual reporting and disclosing of the electing organization's permissible lobbying expenditures and its actual expenditures, thus creating an added administrative and fiscal burden for the organization.

The new test works as follows: first, an electing organization's "exempt purpose expenditures" are calculated. Generally, this includes all the amounts paid or incurred to achieve the purposes of the organization which qualify it to be tax-exempt plus all the amounts paid or incurred to influence legislation. "Exempt purpose expenditures" do not generally include money paid for fundraising by a separate fundraising unit of the organization.

The new test then permits an electing organization to spend, free of tax, up to 25% of the "exempt purpose expenditures" for so-called "grass roots" lobbying and between 5% and 20% of its "exempt purpose expenditures" for direct lobbying, the percentage depending on how large the annual expenditure is. (20% of the first $500,000; 15% of the second $500,000; 10% of the third $500,000; and 5% of the remaining annual expenditures).

If an organization exceeds these percentages it is still permitted to lobby so long as the organization pays an excise tax of 25% of the excesss. Under the new test, an organization that pays this excise tax will not lose its tax exempt status unless its average political expenditures over a four year period is more than 150% of the nontaxable lobbying amount.

"Grass roots" lobbying is defined as attempting to influence legislation by attempting to affect the opinions of the general public, for example, by distributing handbills or by encouraging members of the organization in a newsletter to urge others to contact legislators or government employees.

Direct lobbying includes any attempt to influence legislation by communicating with any legislator, governmental official or employee who may participate in the formulation of legislation. For example, encouraging members of the organization through a newsletter to contact Congressmen to support or oppose a proposed law would be direct lobbying.

Under the new test some additional types of political activity have been identified which can be engaged in without limitation: (1) An organization can lobby in "self-defense." That is, there are no restrictions against communication with legislators about decisions that might affect, for example, the existence, powers, duties or tax exempt status of the organization. However, this "self-defense" exception does not include lobbying for continued appropriations for programs from which an organization receives grants. (2) Communicating with members about legislation of direct interest to the organization is not restricted so long as members are not urged to contact legislators. (3) Organizations can communicate directly with government personnel about any concerns other than legislation without limit. This means there is no restriction, for example, on speaking with government personnel about the formulation of regulations.

The scope of the limitations of political activities as outlined here can be complicated under either test. If there is a question about whether a particular activity is covered or not it is best to seek the advice of an expert in tax matters.

BIBLIOGRAPHY

Addison, Max R., and Haggerty, Moore. "Advocates on Advocacy: Defining Three Approaches — Citizen, Legal and Systems Advocacy," **Amicus**. National Center for Law and the Handicapped, 1 (4), 9-16, 1976.

Bernstein, Jack, and Clarke, Brenda. **Advocacy for the Mentally Retarded**, composed of three booklets, "Community Organization," "Strategies for Problem Solving," and "Public Relations." New York State Association for Retarded Citizens, Inc. and Protection and Advocacy System for Developmental Disabilities, Inc., New York, 1976.

Biklen, Douglas. "Advocacy Comes of Age." **Exceptional Children**, 42 (6), 308- 313, 1976.

Biklen, Douglas. **Let Our Children Go: An Organizing Manual for Parents and Advocates**. (Human Policy Press, P.O. Box 127, Syracuse, New York), 1974.

Brewer, Garry, and Kakalik, James. **Handicapped Children: Strategies for Improving Services**. McGraw-Hill, New York, 1979.

Center for Public Representation. **Meeting Legal Needs Without Lawyers: An Experiment in Advocacy Training**. 20 pp. (Center for Public Representation, Madison, Wisconsin).

Children's Defense Fund. **It's Time to Stand Up for Your Children: A Parent's Guide to Child Advocacy**, (Children's Defense Fund, Washington D.C.), 1978.

Children's Defense Fund. "Where Do You Look? Whom Do You Ask? How Do You Know?" Resources for Child Advocates, 1978.

Cutler, Barbara Coyne. **Unraveling the Special Education Maze: An Action Guide for Parents**. Research Press, Champaign, Illinois, 1981.

Des Jardins, Charlotte. **How to Get Services by Being Assertive**. Coordinating Council for Handicapped Children, 220 S. State St., Chicago, Illinois, 1980.

Des Jardins, Charlotte. **How to Organize an Effective Parent Group and Move Bureaucracies**. Coordinating Council for Handicapped Children, 220 S. State St., Chicago, Illinois, 1980.

Kahn, Alfred J., Kamerman, Sheila B., and McGowan, Brenda G. **Child Advocacy: Report of a National Baseline Study**. (DHEW Publication No. OCD 73-18). U.S. Government Printing Office, Washington, D.C., 1973.

Moore, Dana. **Case and Systems Advocacy**. Dede Wallace Center, P.O. Box 40487, Nashville, Tennessee 37204, 1976.

Norley, Dolores B. "The Care and Feeding of Legislators," **Exceptional Parent**, 2 (3), 29-30, 1972.

Schimmel, David, and Fischer, Louis. **The Rights of Parents in the Education of Their Children**. The National Committee for Citizens in Education, Suite 410, Wilde Lake Village Green, Columbia, Maryland 21044, 1977.

Turnbull, H. Rutherford and Turnbull, Ann. **Free Appropriate Public Education: Law and Implemention**. Love Publishing Company, Denver, Colorado, 1978.

Varela, Rita A. **Participating Citizens**. The American Coalition of Citizens with Disabilities, Inc., 1200 15th Street, N.W., Suite 201, Washington, D.C. 20005, 1980.

Wolfensberger, Wolf. **The Third Stage in the Evolution of Voluntary Associations for the Mentally Retarded**. National Institute on Mental Retardation, 4700 Keele St., Downsview, Toronto, Ontario M3J1P3, 1973.

Wolfensberger, Wolf. **Normalization: The Principle of Normalization in Human Services**. National Institute on Mental Retardation, 4700 Keele St., Downsview, Toronto, Ontario M3J1P3, 1972.

LITIGATION

Kotin, Lawrence. **Due Process in Special Education: Legal Perspectives: The State of the States, P.L. 94-142 and Systems Design**. Research Institute for Educational Problems, Cambridge, MA, 1976.

Legal Change for the Handicapped Through Litigation, edited by Alan Abeson, Council for Exceptional Children, 1920 Association Drive, Reston, VA, 1973.

Levine, A.H., and Cary, E., **The Rights of Students**. Avon Books, New York, NY, 1977.

Public Policy and the Education of Exceptional Children, edited by Frederick J. Weintraub, Alan Abeson, Joseph Ballard, Martin L. LaVor, Council for Exceptional Children, Reston, VA, 1976.

Turnbull, Ann. **Free Appropriate Public Education: Law and Implementation**. Love Publishing Co., Denver, CO, 1978.

POLITICAL ACTIVITIES AND IRS

Limitations on Political Activities by Non-Profit Corporations. Legal Information Project of the Community Congress of San Diego, Inc. San Diego, CA, 1979.

1982 U.S. Master Tax Guide. Commerce Clearing House, Inc., 4025 W. Peterson Ave., Chicago, IL 60646, 1982

Focus on Special Education Legal Practices: A Quarterly Information Sheet Providing Specialized Commentary for Organizations Serving Handicapped People, edited by David C. Trott, Esq., Closer Look, Box 1492, Washington, D.C. 20013. (Vol. I, No. 3 deals with lobbying and tax-exempt status.) 1981.

BIBLIOGRAPHY

Human Services Bibliography Series: Advocacy for Citizens Using Human Services Agencies. Project Share, A National Clearinghouse for Improving the Management of Human Services, P.O. Box 2309, Rockville, MD 20852, September 1981.

COALITION QUARTERLY

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PERSONNEL PRIMER

STAFFING THE PARENT CENTER

This issue of **Coalition Quarterly** discusses personnel management in two broad areas — those issues governed by law, and the common personnel practices that have evolved among parent centers.

The first article, "Personnel Law," prepared by Robert Crabtree, Esq., outlines basic legal requirements concerning wages, benefits and working conditions; anti-discrimination laws; and general principles governing the development of sound personnel documents. He stresses the importance of documentation in every aspect of employer-employee relations, and notes precautions to be observed in interviewing procedures.

Even though many issues related to staffing and management are legally spelled out, many other issues are left to the discretion of center directors, to be determined according to the needs of the work to be done and the needs of the workers. The second article highlights personnel practices that parent centers have adopted in response to the nature of the work they do and to the general characteristics of the workers.

It is impossible to examine thoroughly personnel policies and practices within the scope of this issue; however, we welcome your questions and invite you to call us if you need more detailed information or sample documents.

PERSONNEL LAW

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Parent Centers, like other small businesses, are subject to a variety of laws and regulations that affect their relations with employees. In most cases these laws require no more than a Center would do as a matter of common sense, fairness and the maintenance of congenial and productive working relationships. Some impose burdens of paperwork and expense; others present difficult choices for the employer-Center between preserving the employer's rights to make decisions and avoiding the appearance of belittling or denying employees' rights.

The major laws relating to personnel fall into two groups: those designed to prevent discrimination and those concerned with wages, benefits and working conditions. Center employers should, of course, be familiar with these laws (several are summarized below) and take steps to comply with them. They should also develop policies and practices which create an atmosphere of openness and participation and minimize misunderstandings with employees.

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The Importance of Documentation

One of the most important tools to achieve this openness is to have a written personnel policy. Even if a Center has relatively few employees, a written statement of its policies regarding wages, benefits, rules for the workplace, disciplinary procedures and the like is helpful. As the Center grows in size, such a document becomes not merely desirable but essential to good working relations. Personnel policies are required to be in writing by many funding sources, both governmental and private, and are almost always requested by auditors for larger programs.

A Center should also develop a written job description for each position defining concisely an employee's duties and responsibilities, the supervisory structure, qualifications for the position, salary, and what the employee must do for advancement at the Center.

Along with personnel policy statements and job descriptions, a Center should maintain an orderly system of records covering its relations with individual employees. This documentation is especially important to protect against charges of discrimination in hiring or firing. Concerning an employee's disciplinary termination, for example, a Center is well protected against discrimination claims where its employee file shows a systematic attempt to work out problems with the employee using progressively more severe disciplinary measures, culminating finally with termination. Copies of filed reports should be given to the employee. Of course, some types of misconduct call for immediate termination. If this occurs, a letter should be sent to the ex-employee and filed as soon as possible specifically stating the reason for the firing.

Major Anti-Discrimination Laws

1. **The Civil Rights Act of 1969, Title VII** (as amended by the Equal Employment Opportunity Act of 1972) applies to employers of 15 or more employees. It prohibits discrimination against job applicants and employees because of race, color, religion, sex, or national origin in any term, condition or privilege of employment. Employers must post a notice telling how to file charges with the enforcing agency, the Equal Employment Opportunity Commission (EEOC), and must eliminate "artificial, arbitrary and unnecessary barriers to employment."

   The EEOC will try to conciliate a charge made against an employer, but if that fails, may file a civil action in Federal court to enforce the law. Job applicants and employees may file a complaint in the EEOC and may also sue employers directly in court.

   Employers in violation may be ordered to make retroactive salary payments and pay the claimant's attorney's fees and expenses as well as to submit a plan for changing their employment practices.

2. **The Federal Age Discrimination In Employment Act of 1967** (as amended in 1978) provides the same protections as the Civil Rights Act to persons age 40-70 where the employer has 25 or more employees.

3. Federal contractors and subcontractors with contracts of $10,000 or more must engage in affirmative action programs (generally identifying and changing practices with discriminatory effects and positively recruiting and providing an accepting work environment for women and minorities). The affirmative action program must be in writing and will be monitored by a Federal compliance agency if the contractor has 50 or more employees and the contract is $50,000 or more. "Contracts" does not include "grants." Executive Order 11246 (amended by Executive Order 11375).

4. Federal contractors and subcontractors of $2,500 or more and grant recipients are prohibited by the **Rehabilitation Act of 1973 — Sections 503 and 504** from discriminating on the basis of handicaps and must develop affirmative action programs.

5. Under the **Vietnam Era Veteran's Readjustment Assistance Act of 1974 — Section 402**, Federal contractors and subcontractors are prohibited from discriminating against qualified Vietnam Era Veterans during the first four years after discharge and against Vietnam Veterans disabled 30% or more throughout their work-life. Affirmative action programs are also required.

   In general, the best protection against charges of discrimination by unsuccessful job applicants is to limit questions in the hiring process to those seeking information which is really necessary to evaluate the applicant's qualifications and avoid those that are unnecessary. Inquiries about race, handicap, etc. should be used only as part of an affirmative action program. As for terminated employees, a systematic program of employee discipline and record-keeping as described above is the best protection. Anti-discrimination laws do not prohibit firing employees for just cause where rational disciplinary procedures have been followed.

Laws Concerning Wages, Benefits and Working Conditions

1. **Fair Labor Standards Act of 1938**, as amended by the Education Amendments of 1972, and the laws of most states establish certain requirements relating to minimum wages, overtime pay, and other basic provisions of the work environment. Executive, administrative and professional employees are exempt from the FLSA's provisions.

Particular provisions of the FLSA include these: (a) a minimum wage of $3.35 hour (as of this writing); (b) overtime pay at 1½ times the regular rate after 40 hours; (c) provisions restricting children age 14 and 15 to work limited hours outside of school hours; (d) provisions prohibiting discrimination on the basis of sex where employees are doing substantially equal work with equal skill, effort and responsibility.

The importance under the FLSA of keeping simple, clear records of employees' time and wages paid cannot be overstated. The enforcing agency, the Wage and Hour Division of the U.S. Department of Labor, sometimes treats poor record-keeping itself as a sign that the law is being violated. Penalties include payment of back wages, injunctive relief, and sometimes payment of additional money damages. In particularly egregious cases, criminal fines may be imposed.

2. Federal and state laws combine to provide unemployment insurance benefits under the **Federal Unemployment Insurance Tax Act of 1939** and the **Social Security Act of 1935**, as amended. Not-for-profit organizations must participate in most state programs if they employ a sufficient, usually small, number of people.

   In most states, an employer may either self-insure or contribute to an unemployment insurance fund. A center should weigh carefully the possible cost of having to pay benefits to an ex-employee against the certain costs of contributing to an insurance fund to decide between the two alternatives.

   Usually a terminated employee will be eligible for benefits unless she he left voluntarily without good cause, or was fired for misconduct that was against the interests of the employer. The ex-employee must be able and available to work at employment comparable to the job she, he has left, but need not accept (1) a job open because of a labor dispute or (2) work where the wages or working conditions are lower than standards in the area or (3) work offered on the condition that she he join a company union or that she he not join a union.

   The options available to Centers which are tax-exempt under Sec. 501(c)(3) regarding social security taxes will be discussed in the next issue of ***Coalition Quarterly***.

3. **Worker's Compensation** laws apply to employers in every state, although typically a state will exempt organizations with only a small number of full-time employees. These laws are to protect against the consequences of injuries sustained on the job, usually including those occurring while traveling to or from the job. The employer's responsibility to provide benefits attaches regardless of who caused the injury.

   Injured employees, and in case of a death, their dependents, are typically entitled to one-half to two-thirds of their weekly wage plus hospital and medical benefits. In return, employees give up their rights to sue their employers, but they may sue any person who negligently caused the injury. If such a suit is successful, any payments they recover must first be used to reimburse the employer or his insurance company, and the remainder belongs to the employee.

   Centers often use consultants who may not be considered employees covered by the worker's compensation provisions because they are "independent contractors." Generally speaking, independent contractors are persons who agree to produce a product, but remain independent of the employer and do not submit to his or her particular instructions concerning how to produce the product.

   Most states require employers to carry worker's compensation insurance and do not give them the option of being self-insured. The potential costs to an employer of having to pay a claim itself are so great in any event that it is ill-advised not to carry insurance.

4. Parent Centers, which are typically small, are unlikely to face union organizing campaigns, but should not consider themselves immune, especially if they grow in size. Law defining the rights of employees of employers "in interstate commerce" is found in the **National Labor Relations Act**. Other employers are often covered by state laws similar to the NLRA. Should a Center be confronted by requests that a labor organization be recognized as representing the Center's employees, the Center should consult with an attorney or other expert in the area of labor relations.

   With or without a union, a Center is well-advised to have fair and sensible procedures for handling discipline, disputes over wages and working conditions, and individual employee grievances. As dedicated and professional as employees of Parent Centers are, they have the same needs and rights as any other employees. If those needs and rights are not honored, Parent Centers, like other employers, run a serious risk of low morale and burnout which in turn undermine a Center's ability to serve families in need.

PERSONNEL PRACTICES

Introduction

In addition to the legal items Mr. Crabtree discusses, other aspects of personnel management need clarification from the beginning to assure smooth Center functioning. Written personnel policies and job descriptions help define these areas.

Beyond statements of compliance with the laws governing the Center's relationship with its employees, written personnel policies include details on operating procedures designed to reflect each Center's philosophy and priorities in personnel management. These policies should be based upon the needs of the Center itself, rather than upon the staff profile at a given time. It is easy to assume that certain problems are not likely to plague one's own Center if the staff is dedicated and skilled. There is no guarantee, however, that such a situation will remain stable forever.

Job descriptions further specify employer-employee roles in day-to-day operations. This article discusses both personnel policies and job descriptions as they apply to parent centers.

Personnel Policies

Personnel policies are a statement of mutual expectations. They provide guidelines for judgements and should reflect the Center's commitments and philosophy. Since personnel policies are often similar for most non-profit organizations, request copies from other parent centers and similar organizations, preferably larger and older than your own, before embarking on the task of writing them. Excellent resources for additional information are available from the Grantsmanship Center, 1081 South Grant Ave., Los Angeles, CA 90015. We especially recommend the publications **Personnel Policies for Your Agency: Get Them In Writing Now,** and **How To Design Your Agency's Employee Benefits Program.** The following discussion highlights those components of personnel policies that may be less standardized or that have particular relevance to parent centers.

Hiring — Whenever possible, Centers have been careful to maintain their original volunteer staff in paid positions when, and if, funding becomes available. Experience has shown that it is especially important from the beginning that there be a single strong leader who is in that position by consensus, and this person should be the first one to assume a paid position. Usually such a leader has been instrumental in founding the center, obtaining initial funding, and in assuring its continuance. In most proposals for funding, key personnel are identified and money is awarded on the condition that those personnel be involved as specified in the proposal.

Occasionally friction develops when some staff can go on a payroll and others must continue as volunteers. Care should be taken to build in rewards for volunteers, and, whenever feasible, to give them priority when adding to the payroll. In addition to monetary rewards, volunteer and paid staff are often motivated by such things as recognition, achievement, and opportunities for personal development and challenge.

Often Centers downplay the importance of academic credentials and emphasize volunteer experience. However, some areas, not related primarily to the content of the work, may require more formal training: for example, financial management, office management, supervision, writing, and research skills. Overall staffing patterns should allow for a range of talents and abilities.

Affirmative Action — An affirmative action statement in writing may be legally required for your organization. (See previous article for guidelines). Affirmative action requires a more active seeking out of ways to employ women, minorities, veterans, and handicapped persons than a simple statement of non-discrimination. Usually, additional financial and time commitments are required.

Even if not required, many Parent Centers practice affirmative action for parents of children with handicaps (in keeping with their overall intention to maintain a parent perspective) and for disabled adults (as a means of expanding employment opportunities).

Setting Pay Levels — This task is a delicate one. Salaries are often predetermined by specific requirements of contracts or grants. One Parent Center stressed that, "At the outset, care should be taken to think in terms of sexist policies. People are likely to undervalue themselves because they are women, especially if they work part-time and continue to do much the same work they did previously on a volunteer basis."

Scales should reflect current levels in state and federal government, as well as salarly levels and cost of living in one's own community. Contacting another Parent Center and your local United Way organizations will offer some guidelines before establishing salary levels.

A method for granting salary increases should be spelled out. These are usually made according to an automatic schedule, presuming satisfactory work performance, or by merit review. Specifications for times when salaries will advance or be reviewed, as well as criteria for determining pay, should also be included. Each job should have a salary range to set limits on salary progression. This projection will help predict payroll costs, and give employees the security that pay will be equitably adjusted on a regular basis.

Some mention should be made of cost of living increments. Funding sources seldom expand enough to totally protect Center employees from the effects of inflation, but sound financial planning should permit a small allowance for this purpose, even if in combination with merit increases.

Benefits — In addition to programs in which, by law, the employer must participate, there are other benefit options which an employer may offer as ways to augment the salary, such as the obvious benefits of holidays and vacation time. Remember, benefits usually cost money, so calculate carefully the potential cost before offering them.

In developing benefit packages, consider the needs of the workers; for example, if they are predominantly young, they may appreciate maternity and educational benefits, as well as consideration given to days off which correspond to school holidays. Older staff may appreciate life insurance and retirement plans. Health and dental plans have universal appeal.

Credit union advantages are not difficult to set up, do not cost the company anything, and employees appreciate the service. Often Centers receive vouchers for college courses in exchange for supervising work-study students. These can be offered to employees without cost to the Center. Don't overlook opportunities for training which are offered through the Center itself and do explore other avenues of educational assistance.

Promotion — Opportunities for advancement and change within an organization are good for staff morale and every effort should be made to promote from within the existing ranks of staff and volunteers. Maximize talents of the staff by using the Center itself as a means of "learning by doing" through apprenticeship programs. For example, Centers often start workers in a receptionist position as a means of familiarizing them with basic procedures, or give a learner opportunities to participate in panel discussions after observing more experienced staff at speaking engagements. Such training and observation may enable the worker to gain the skills needed for promotion when the opportunity arises.

Delegation of Authority — Centers agree that to bring out the leadership potential of workers, they must be given meaningful responsibilities from the beginning. The continuity and stability of the Center depend upon leadership development.

Probationary Period — A three to six month probationary period offers opportunity for mutual evaluation for workers and is also valuable in cases of promotion. Remember the Peter Principle!

Work Schedules — Although most Centers keep regular daily hours, there are usually more part-time than full-time workers. Staff members who are most involved in direct advocacy or training need a degree of flexibility in the hours they will be in the office. It is vital, however, that events outside the office and in-office meetings be scheduled so that there is adequate coverage in the office at all times. Ideally, there should be at least one full-time person in the office the greatest percentage of his/her time in order to assure continuity. Whenever possible, it is preferable to have part-time workers in the office daily, rather than two or three full days per week. Even under the best of conditions, care must be taken to build in opportunities for all staff to be present at the same time to facilitate communication and continuity.

Job Descriptions

Typically, workers in parent centers are action-minded and service-oriented and the development of written operating documents has been of secondary priority. This was especially true immediately following the passage of P.L. 94-142 when the enthusiasm and commitment of parents provided the necessary energy and direction to create and maintain effective programs. Often staffs were small, and little differentiation of job descriptions was needed. Indeed, a spirit of equality and democracy prevailed, with all staff basically having the same job descriptions, although seldom written down. As Centers grow, and differentiation becomes necessary, viable job descriptions increase the chances of maintaining this spirit of cooperation and enthusiasm by providing paid and volunteer workers with definitions of their responsibilities. Such clear lines of responsibility form a structure which allows workers to continue in a genuinely caring and effective manner.

It is not uncommon for workers in parent centers to have more than one job title — one a generic, internal title, and a second, functional title assigned to a particular grant or contract which is subject to change when a temporary assignment is completed. Internally, a worker may be referred to as a "resource parent" or "information specialist," while at the same time acting as a project director for a particular grant.

For this reason, the job description must be flexible enough to allow for changes and should be updated as needed. Annual review of job descriptions as well as pay levels and schedules has proven helpful in established centers.

Job descriptions should contain the following information:

- title of position, supervisor, overall duties to be performed, and amount of time involved;
- necessary skills (technical, communication and interpersonal, or managerial);
- concise and clear statements of the tasks involved in performing the job;
- a specified time when evaluation will be performed;
- salary range.

Volunteers

A valuable part of the work of many Parent Centers is done by volunteers. They work out of a sense of identification with the Center's philosophy and goals, a desire for personal fulfillment and an urge to serve.

The relationship between the volunteer and the center should be regarded as contractual — everyone from the first must understand that a volunteer's commitment is as serious as that of a paid worker.

Some Centers have written agreements, signed by the volunteer worker and the Center, that spell out their mutual obligations and provide a basis for understanding. Space does not allow us to include samples, but we will be happy to send them on request.

The federal government recognizes the work of vounteers and grants them some of the same consideration given to paid workers. The IRS code allows volunteers to deduct certain travel, gas, food, and lodging expenses incurred on the job from their taxes. The Civil Service Code allows applicants for government jobs to include relevant volunteer work in their employment history.

Involvement and motivation are as vital to good volunteer management as to paid staff. Since they are not motivated by a paycheck, volunteers are unlikely to continue in jobs they think are unimportant. Efforts to keep them involved and to develop their skills and talents will help keep interest and enthusiasm strong.

In addition to Voluntary Action Centers, which are run by the United Way, centers have been successful in recruiting volunteers from the following sources: local colleges and universities; parents who have been trained or helped by the center are often willing volunteers; elderly or retired persons; disabled adults.

FOLLOW UP ASSISTANCE

Dear Reader,

Your input is important to us! In order to supply you with the information you need, we need to hear from you. Let us know if you have found the *Coalition Quarterly* helpful and how you have used it. If there are any topics you would particularly appreciate being covered, please let us know that, too. The more responses we receive, the better we can suit the information to your needs.

Also, if information contained in any of the issues stimulated further questions or a need for more in-depth information, please call or write to us at the Federation. We will do our best to provide you with the assistance you need. Contact:

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FUTURE ISSUES

Publication and distribution of *Coalition Quarterly* may be delayed for a few months after March, 1982. Please be patient — distribution will resume in the near future.

BIBLIOGRAPHY

Hummel, Joan. **Starting and Running a Non-Profit Organization.** University of Minnesota Press, Minneapolis, MN, 1980.

Jensen, Jerry. "How to Design Your Agency's Employee Benefits Program," **Grantsmanship Center News,** Reprint Series on Management, 1031 S. Grand Avenue, Los Angeles, CA 90015, 1979.

Jensen, Jerry. "Personnel Policies For Your Agency: Get Them In Writing Now," **Grantsmanship Center News,** Reprint Series on Management, 1031 S. Grand Avenue, Los Angeles, CA 90015, 1979.

Loen, Ernest. **Personnel Management Guide for Small Business.** Small Business Administration, Washington, D.C., 1974.

Wilson, Marlene. **Effective Management of Volunteer Programs.** Volunteer Management Associates, 279 S. Cedar Brook Road, Boulder, CO 80302, 1979.

Wilson, Marlene. **Survival Skills for Managers.** Volunteer Management Associates, 279 S. Cedar Brook Road, Boulder, CO 80302, 1981.

COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

Volume II, Numbers 2 and 3 *Fall 1982*

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INTRODUCTION

This issue of ***Coalition Quarterly*** and the next one will present basic information about funding sources available to coalitions of organizations representing people with disabilities. Raising money is somewhat more challenging for a coalition than it is for most other nonprofit organizations because a coalition, by its very nature, must avoid those kinds of fundraising activities that would put it in competition with its own member groups. Thus, such familiar efforts as direct mail appeals, annual dues, and walk-a-thons may be out of the question, depending on the particular coalition.

The centers being operated successfully by coalitions of parents of children with disabilities have been funded primarily by federal and state government grants. Several centers have also developed alternative or supplemental funding resources. The next issue of ***Coalition Quarterly*** will summarize relevant experience with government grants, including information about eligibility, preparation, and accountability. This issue offers suggestions on the non-governmental resources.

We have devoted this double issue primarily to the three most significant sources of private funds: foundations, corporate gifts, and the United Way. In addition, we have included suggestions about publication as an ongoing resource.

In the presentation of foundation and corporate grants, we have included an interview with an executive with a large metropolitan foundation, conducted by the editor, and an article about one center's experience with such funding, prepared by three persons from that center. In the discussion of United Way possibilities, the editor describes one center's experience with one type of United Way funding and staff members from another center describe the process for membership application, a second form of United Way funding. In a final article, one center director presents a step-by-step guide for launching a financially successful publishing venture. These articles show how some coalitions have used the resources of their local community and their own talents to augment their funding base.

FOUNDATION FUNDING

INTERVIEW

In the hope of demystifying the process of obtaining money from foundations, the editor of ***Coalition Quarterly*** interviewed a foundation executive in a large metropolitan area. The foundation representative gave a brief personal overview of the foundation world. While some of her comments reflect her involvement in a particular foundation, most are relevant to all types of foundations, especially professionally staffed, community-oriented ones. Following are highlights of the discussion between the ***Coalition Quarterly*** editor and the foundation executive.

FOUNDATION EXECUTIVE: ... In the world of private philanthropy, foundation giving represents about five percent of the total contributions. The biggest givers are still individuals, and the biggest recipients are churches. What foundations have been able to do is to organize their giving in such a way that the impact of their modest dollars is quite high ... I hope we will find more creative ways of financing projects, and that people will develop new types of organizations. Where before, issues of turf kept organizations separate, I think we will now see more organizations coming together ... Some may merge, others may cut costs by sharing space or by doing bulk purchasing. I also think there have been missed opportunities to make money because people felt they could not ask clients for money. You can charge. Sometimes charging people is a way of connecting them more strongly with the service.

In relation to parent centers, advocacy has always been a difficult area to fund because it is not thought of as a direct service. It is difficult to document how someone has been helped through advocacy efforts; consequently, it is difficult to demonstrate the results to boards and others. People would rather support things they can see — numbers, buildings, a changed school system. The fact that advocacy has not been liberally funded in the past may now be to its benefit. Without large infusions of money advocacy organizations have still been successful. They have been forced to be more creative, depending on volunteers, on people's dedication to a cause, and on strong client constituencies. I'm not saying that money is not necessary. It is. However, parent centers need to determine what in their program is fundable.

CQ: Is it appropriate to ask a funding source which of the many activities performed in a parent center they would be most likely to fund?

FOUNDATION EXECUTIVE: In our assessment of a proposed project, we look for a clear statement of organizational purpose and priorities. Part of the organization's homework is to know its priorities and to match them with available funds. Their next task is to convince the funding source of the reasons why this is needed and explain how it fits into the framework of the organization.

CQ: What are the differences among the various types of foundations?

FOUNDATION: There are several major differences. A foundation may be privately administered by a corporation or a family. As such, it can have either a distinct programmatic interest or a geographical focus. A public community foundation, on the other hand, has an obligation to respond to the broad charitable needs of its own community, rather than to hold to a specific program focus. In doing your homework, there is a wide range of information available in libraries throughout the country. At the top of any grantseeker's list would be the publications of the Foundation Center.* With the help of their directories, you should find those foundations that are interested in the area in which your organization is involved. How much money have they given? What is the size of the average grant? To what organizations? For what purpose?

CQ: What happens to a proposal after you receive it?

FOUNDATION: The proposals that fall within our guidelines are assigned to a program officer, who meets with the applicants to determine that their organization is healthy, that it is addressing a real need, and that it is capable of managing the grant. Site visits are usually a part of the evaluation process because they give a better sense of the organization and what it is about.

One thing you should know is that it is very rare for a new organization, without an established track record, to get funds. Groups are not always immediately successful. You have to stick to it and keep coming. If your organization has had previous funding, those sources should be listed and discussed in the proposal.

CQ: In summing up, is there any other general advice you would have for someone who has never approached a foundation?

FOUNDATION: I think there's a lot of mystery surrounding getting money. There are people who sit on both sides of the desk. The money is there to be given to those groups who have the best chance of advancing the interests of a particular foundation. A foundation wants to see a group that:

- is well organized;
- has its priorities straight;
- is well managed;
- has a good board of directors;
- has a knowledgeable staff; and
- has satisfied consumers.

Our board does not like to be approached by individuals who have proposals pending. That's why they employ a staff. I would advise most people who are applying at large, staffed foundations not to approach the volunteer board members, but to work directly with the staff. Make sure your proposal is something the foundation will fund, and you'll get a good hearing.

PARENT COALITIONS AND PRIVATE SECTOR FUNDING

Paula Goldberg, Betty Binkard and Marge Goldberg
PACER Center, Minneapolis, Minnesota

An austere financial climate and substantial cuts in available funding from traditional sources make today a logical period for parent groups to develop and establish strong and ongoing partnerships with private corporations and foundations.

While the competition for these grants is intense, and though the private sector cannot possibly meet the total financial needs of all nonprofit organizations, parent coalitions representing handicapped students can begin to turn to foundations and corporations for at least supplemental sources of financing. Since December, 1981, PACER has received eleven grants, of varying size, as well as in-kind contributions from corporations and foundations, a direct result of having increased the number of proposals submitted.

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* NOTE: See "RESOURCES," page 10, for complete address and telephone number. "Researching Foundations, Parts I and II," available through the Grantsmanship Center Reprint Series, are excellent guides to the Foundation Center's publications. See Bibliography.

Preparation

PACER Center has discovered several strategies to enhance an organization's chance of success. One such discovery has been a realization of the great variety among corporations and foundations — in their philosophies, in the types of programs they tend to support, and in the range in size of their contributions. Very few are willing to support an agency's total program. Some may be hesitant to make grants to programs that promote system change. Some prefer to give direct monetary grants while others wish to make contributions of furniture, supplies, or a product they manufacture.

Therefore, as a time-saving first step, it is wise to discover in advance the variations just mentioned, before you make initial contact. As an aid to your homework, books prepared by a council on foundations may be available in your state; these give details on the funding sources within a particular community. Libraries also contain reference volumes with information on the types of assistance offered by private sources.

Since the grant writing process is a lengthy one, groups must ensure that their efforts are concentrated on those sources of funding which offer a hope of success. Further, by discovering the foundation's or corporation's philosophy, a group can then shape its proposal to best fit that philosophy.

After the homework stage, the next step is to contact the specific foundation or business identified. The initial contact person at a foundation may be its director or a staff member. With a corporation, ask for the name of the person responsible for contributions. Or, a second contact within a corporation may be the directors of an employees' contribution or service committee.

Making Contact

During the initial conversations, several areas should be covered. First, you must establish that your coalition is a nonprofit, tax exempt corporation since such characteristics are required in order to receive funds from the private sector.

Second, your sense of your program's worth must be conveyed. Be ready to present in factual terms the number of persons who are in need of your service and why, what your program offers that is unique, the number of people you have served already, and specific details about what has been accomplished through receipt of the service. This array of information should not be lengthy, but must convey a rational justification for receiving a grant or donation.

Finally, there are a number of questions you will find helpful to ask:

1. Does this foundation/corporation provide general operating support grants or does it prefer funding specific projects? General operating support means the funds can be used for the present parent project and the general budget. If it funds only specific projects, you should describe several specific projects for which you are seeking funds. Before calling, be sure to set priorities for your list of specific projects. You might then suggest these as examples that you feel need to be funded. The foundation staff person may comment on how appropriate they feel the specific project may be for foundation support.

2. Are there written guidelines for grant proposals? If not, ask what the length and format of your proposal should be, how many copies are needed, and to whom you should send them. Most foundations and corporations do not want long extensive grant proposals. Grant request guidelines are often included in the organization's annual report.

3. Would it be advisable to meet with the staff person or the employee volunteer committee? It's often helpful, but not always necessary, to develop a relationship with a staff person from the foundation or corporation.

4. What is the timeline for grants? When are the grants due? Some foundations review grants every month, others four times a year, and some only once a year.

5. What is the usual amount of funding given for similar projects? Does this foundation/corporation fund projects for $1,000 or would the staff person recommend submitting a grant for $10,000? It is important to know the limit for grants from any source, since proposals which exceed the limit may be rejected automatically. In some cases, if the total cost of a proposal exceeds the grant limit, you may be offered a matching grant, or the project might be funded for a shorter time period for less money. On rare occasions, you may receive more money than you originally requested. This has happened to PACER twice recently. In one case, PACER was told that a corporation had a $5,000 grant limit. After presenting PACER's needs to the employee committee, the committee decided to allocate what was actually required for the project, an additional $3,000.

6. When will the grants be considered? Knowing when the board or group meets will give you an idea of when you will hear about the proposal. Also, you then can ask when it is appropriate to call back and learn the results of the meeting.

7. Does the corporation view it as helpful if its employees are involved in the parent coalition? One of your board members may work for that particular corporation or some employees of that business may have attended your training workshop. You could mention such ties to the staff person during the initial contact, and again in the proposal's cover letter.

Employee Involvement

Many corporations tend to support groups that benefit their employees or in which their employees are involved as volunteers.* The board of directors of your parent coalition can be an important source of information and support for private sector funding. If an employee is a member of your board, more weight may be given to a grant proposal submitted to that corporation. In adding new members to your board, it might be advisable to look to people who are employed in corporations.

In addition, many corporations may inquire if your coalition has served any of their employees during the year. A method of documenting this information can be developed by parent centers. During the last year, PACER Center has been asking parents who attend workshops to help by answering a survey and returning it at the end of the workshop. The survey provides information to PACER about where the parents or members of their families are employed. These simple surveys are used in two ways. The first is to document to corporations that a certain number of their employees have recently used PACER services. A second is to learn about businesses, through workshop participants, who might be receptive to PACER's request for assistance. Contact PACER for a sample of this form.

Written Proposal

After the initial contact, either by telephone or in person, the usual procedure is to submit a written grant request. A useful guide, entitled "Program Planning and Proposal Writing," by Norton J. Kiritz, is available from the Grantsmanship Center, 1031 South Grand Avenue, Los Angeles, CA 90015.

The following guide may be helpful in preparing your grant proposal:

1. **A cover letter:** this is usually one to three pages long and gives a summary of the proposal and a brief explanation of your organization;

2. **An introduction:** state (a) the amount of funds you are requesting and what they are for, and (b) the history of your organization: explain how you started; whom you serve, how many you serve, the geographic area of your project, your credibility, and what you have accomplished for the last few years;

3. **The specific problem that you will be addressing;**

4. **Documentation of the need for the proposed project;**

5. **List of program goals;**

6. **Methodology:** explain the method for achieving the goals. Describe how many people will be served and how many workshops will be held;

7. **Evaluation:** explain how you plan to evaluate your project. PACER often includes a previous evaluation report in the appendix to demonstrate that parent training has been beneficial;

8. **Budget:** prepare a detailed budget if you are seeking funds for a specific project. If you are requesting funds for general operating support, a detailed budget is usually not required. However, in the appendix include your organization's current operating budget as well as your projected budget for the coming year;

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* NOTE: The Corporate Support Program Research Project conducted for United Way of America surveyed corporate giving in 1981. Their study indicates that the prime motivation for corporate giving is "enlightened self-interest." Ninety percent of the corporations that participated indicated that potential benefit to employees was a very important consideration in determining how much and to whom they gave; eighty-five percent rated employee involvement as important. (As reported in **Giving U.S.A., 27th Annual Issue,** 1982).

9. **Other sources of funds:** it may be useful to explain your organization's funding sources in the cover letter or in the grant proposal itself. Today corporations and foundations look carefully at ways organizations have become efficient and self supporting. For some foundations, it may be beneficial if you can document that your parent group initiated a fund raising campaign from the people you serve or charged fees for some services. Foundations understand that parent coalitions cannot become totally self supporting, given the nature of the people they serve and their role as a coalition. In the appendix you should list those corporations and foundations *you have applied to for funds and those that have funded* your organization in the past.

10. **Appendix:** include the following:
    - Names of board members and vitae of key people in the project;
    - IRS 501(C)(3) form;
    - A certified annual audit;
    - Letters of Support. These are letters from parents you have helped, leaders of disability groups and employees of the corporation which attest to the need for the program and to the respect you have gained in your community. Letters from disability groups should clarify that you are in cooperation with them rather than in competition, and that you do not, in any way, duplicate the work that they do.

Coordination

One of the many strengths of a parent coalition that may appeal to potential funders is its cost effectiveness — it provides training for *all* parents of handicapped children in a given area, regardless of disability.

After the Grant Proposal is Submitted, What Do You Do?

After the grant proposal has been submitted, be sure to call the staff person or employee from the foundation or corporation that you originally contacted. It is often helpful to call five to ten days after the proposal was mailed, to see if it was received and if the staff person has any questions about it. Several telephone calls may be necessary until you receive written or oral notification of the results of their review.

Conclusion

Many businesses and foundations have a limited amount of funds to distribute to organizations. Some corporations tend to fund those organizations that they have always supported in the past. A parent coalition may have to submit proposals for small amounts of funding to many organizations rather than expecting one to provide substantial funding.

We have definitely learned that securing funds from the private sector requires time, energy and a commitment to the needs of handicapped children. However, the requirements are justified by our conviction that parent training does help handicapped children, and must be available to their families. Creativity and perseverance can help you and your organization be successful in the highly competitive world of private sector funding.

For additional information, and for sample forms, contact PACER Center, 4701 Chicago Avenue South, Minneapolis, Minn. 55407, or (612) 827-2966.

UNITED WAY FUNDING

INTRODUCTION: INNOVATIVE PROJECTS

There are two avenues for acquiring United Way funds. Traditionally, organizations receive funds by obtaining membership in their local United Way. Once admitted, they are usually able to obtain funding every year. In addition, United Way agencies in most large urban areas have instituted ways which allow non-traditional, emerging organizations to receive funds through grants for innovative projects, regardless of whether these organizations are United Way members.

We recently spoke with two parent centers, The Southwestern Ohio Coalition for Handicapped Children and Team of Advocates for Special Kids, who have obtained United Way funding. They explained how United Way operates and told us their success stories.

Team of Advocates for Special Kids (TASK) received start-up funds from the Innovative Projects Grant Program developed by the United Way of Orange County, California. Jean Turner, who serves on the board of directors for TASK, encourages parent groups to find out if their local United Way has a similar program.

"The Innovative Projects Grant concept," she informs us, "has been adopted by other United Way agencies across the United States and is a source worth exploring, especially since parent centers offer services which are indeed innovative and non-duplicative." Ms. Turner added that, for those parent groups whose local United Way is unfamiliar with such programs, United Way of Orange County is willing to share its guidelines and policies to assist them in developing a similar program. Inquiries should be addressed to: Dr. Paul Sepulveda, Director of Government Relations, United Way North/South, 3903 Metropolitan Drive, Orange, California 92668.*

The Southwestern Ohio Coalition for Handicapped Children, following the more traditional approach, is in the process of becoming a member of its local United Way. Elizabeth Britten, the coalition's executive director, and her staff, describe their experiences and offer suggestions in the following "Individualized Educational Plan" (IEP)—a format with which most of us are familiar!

IEP FOR A SUCCESSFUL MEMBERSHIP APPLICATION TO THE UNITED WAY

Staff, Southwestern Ohio Coalition for Handicapped Children

Present Level of Parent Center Functioning

Parent Centers represent a relatively new concept in citizen involvement and advocacy which is not universally known. At the same time, to be most effective and to realize their long-range goals, parent centers need a broad base of community support.

Local Options

Private corporate and foundation funding usually does not include general operating costs. In addition, these grants are often limited to capital funds or to one-year special projects.

Public funding requires completion of a formidable application process every year, with small guarantee of success, and it is rarely continued on a long-term basis.

The United Way system represents a rare source of ongoing operating funds. In addition, United Way support represents an endorsement of legitimacy and value by local community leaders which lends high credibility with agencies, businesses and other possible future funding sources. United Way does require participation in time, energy and patience in order to comply with their stringent regulations. However, once a project is accepted by the United Way, it is eligible for their internal ongoing support services.

Goal

Submit a successful application for membership to your local United Way.

Short Term Objectives

Before Application

1. Observe other organizations your local United Way approves, and work to establish a rapport with some of them.
2. Spend energy meeting staff and committee members at meetings and other functions. Remember, the persons who make decisions in the United Way system are volunteer board members. Staff members are also important to know because the way they present your information will influence the volunteers.
3. Obtain a full set of current local United Way membership requirements, annual priorities, written reports, and recommendations. Examine them carefully for insight as to the best way to describe and present your program. For example, our local United Way would not fund "Information and Referral" as they had their own service. There was no local category for "Advocacy" per se, and "Community Education" had a low priority. They did have a higher priority for "Counseling," which included supportive counseling (peer counseling) the year we applied. Therefore, we applied under that category. Since that time, we have been instrumental in assisting the organization to develop a definition of advocacy. "Advocacy for the Disabled" subsequently became a locally approved category and we were able to change our application accordingly. (The National United Way program guide does have a category for "Advocacy").

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* NOTE: Since the United Way only funds locally, please do not send grant proposals unless you meet that requirement.

4. Find someone in your community who knows how your local United Way functions. Use that person as a resource in developing your application. (We enlisted a master's degree student in Community Planning who had worked at the United Way).

During Application

1. Submit a convincing first draft application. Show that without United Way support the citizens of your area would be denied this crucial service. United Way will ask for minimal information at first. However, you will be screened in or out on that material. Your goal is to get through the screening process to the volunteer committee that makes the recommendation.
2. Do not be discouraged initially by printed requirements. Get to work and sell your program. If your application is convincing, you may be able to negotiate some standard requirements. We were able to obtain temporary waivers on annual audit, detailed reporting on client characteristics, and fundraising requirements after we had an opportunity to demonstrate the uniqueness of our service to families of handicapped children.
3. Present your case professionally. Most of the volunteers will be from the business community, and will be interested in facts: previously demonstrated effectiveness in concrete terms.
4. The United Way system looks favorably on "coordinated community resources". Demonstrate how you work with other agencies for mutual enhancement. Get strong endorsements from lay persons.
5. United Way will not fund programs belonging to the public sector, such as public education. Demonstrate how your service is not a duplication of what local education agencies are mandated to do. Whether they do it or not is inconsequential.

Annual Review

1. Fill out all forms. Write thank you letters. Respond to all suggestions in writing.
2. Maintain contact with your volunteer committee chair and liaison persons. Seek assistance as needed with volunteers and staff.

HOW TO RAISE MONEY PAINLESSLY THROUGH PUBLISHING*

Charlotte Des Jardins, Executive Director
Coordinating Council for Handicapped Children

As a parent center which has been serving parents of handicapped children for more than twelve years, we stumbled upon book publishing as a relatively painless way to raise money.

I say "stumble" because making money was not our intention when our volunteer parent coalition took its first publication to the printer in 1969. We printed it because there was nothing available at the time to inform parents of the special education rights of their children. Our first publication, **Your Rights As Parents of A Handicapped Child**, was probably the first rights handbook in the country.

Since public school officials and other public agencies were not making this information available, we decided to take the plunge and do it ourselves on a volunteer basis. A public school psychologist wrote the booklet after researching state rules and regulations, with the assistance of a legal aid lawyer, a Vista worker, and myself. When it was completed, public school and university officials reviewed it for accuracy.

At the printer's suggestion, instead of having the manuscript typeset, we typed it on an electric typewriter and brought it to him "camera ready" for offset printing. The total printing cost for 2,000 copies of the twenty-page booklet was $200, only ten cents per copy.

Although we had planned originally to distribute the booklet without charge, we eventually decided to charge twenty-five cents per booklet. We thought this increase would bring in extra money; we had not counted on the hidden costs of postage, envelopes, and promotion.

During the next two years, we published the 222-page, spiral-bound **Guide to Services for Handicapped Children**, which sold for $1.50, and a 92-page manual entitled, **How To Organize An Effective Parent Group and Move Bureaucracies**, priced at $1.00. The small charge for each book covered only the costs of printing and distribution.

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* NOTE: An expanded version of this article is available upon request from ***Coalition Quarterly***.

Meanwhile, by 1976, our original rights handbook went through three reprints and grew from a twenty-page booklet to a ninety-seven-page book. It cost $1.00 to print and sold for $2.00.

Over the next few years, we updated both our **Guide to Services** and our bestseller, **How to Organize An Effective Parent Group and Move Bureaucracies**. At the same time, we introduced a companion bestseller, **How to Get Services by Being Assertive**. Each of the bestsellers sold for $4.50 per copy, including postage. The price was recently increased to $5.00 per copy, plus $1.00 for postage and handling.

In 1982, we are netting approximately $15,000 a year from our books. It's not a large sum, but it helps finance some of our activities.

In order to make that kind of money, we have to promote our books constantly. We include book brochures in every mailing. We bring our books and brochures with us to meetings, especially to those meetings where we are making presentations. We distribute brochures at every conference on disabilities which is held in our area. We write frequent promotion letters to newsletters of disability organizations, parent groups, professional organizations, and to the local media.

Tips on Publishing As a Means of Raising Funds:

1. Look around your office. Some of the material you have already written, which you are now giving away, may be saleable, either by itself, or combined with other material.
2. In developing written materials, think about the requests for information your office has received. Some of it may be saleable in written form.
3. Write in a simple, factual style. Make it easy to read by organizing the information in block form or outline style, with clear headings.
4. Always include names, addresses, and phone numbers of other organizations that can provide additional information.
5. Have others, including experts from outside your organization, review an early draft in order to improve the material and assure its accuracy.
6. Do not count on getting it all, and getting it perfect the first time. Write it over and over again, and have your reviewers review each draft until it is the best you can possibly do.
7. Get estimates from several printers before you commit yourself to one. Find out where other non-profit organizations have their printing done, and the cost. Ask to see samples of the printer's work before you make a commitment.
8. Be optimistic. Remember, you will get a much better price with large quantities. Find out the cost in quantities of 1000, 2000, 5000, 10,000. Try to figure how much you will need for at least two years. Remember, printing costs will keep going up — never down. If you only print enough to last six months or a year, you may run out while your book is selling its best. You will lose customers, and you may have to pay twenty-five to fifty percent more for the next printing.
9. When you fix the prices of your book, remember those hidden costs: envelopes or book casings, postage or shipping, promotion, and all those copies you will need to give away to reviewers, the press, and to heads of large organizations that you hope will buy in quantity.
10. In order to break even, you need to charge at least double the printing cost. If you want to make extra money, you need to charge three to four times the printing costs.
11. Ask other organizations about their publishing ventures and benefit from their experiences.
12. Investigate special marketing workshops which provide technical assistance to programs funded by the Department of Education, Special Education Programs and Rehabilitative Services. LINC, Inc., for example, assists such organizations in developing a marketable product for publication, and assists in linking them with potential publishers. Further information can be obtained from LINC Resources, Inc., 1875 Morse Road, Suite 225, Columbus, Ohio 43229, 614/263-5462.
13. Promote your publications at every opportunity. Distribute at least 5000 brochures in the first year through mailings, meetings, conferences, and newsletters of other organizations. Remember, the number of sales you make will be in direct proportion to the amount of promotion you do.

14. Include a cut-out order form in the booklet itself for easy reorder. Also include your brochure with every book you send out.

Remember, when you go into the publishing business, you will not only make money painlessly; most important of all, you will be providing a valuable service.

RESOURCES

The Foundation Center, 887 Seventh Avenue, New York, NY 10019, is a national service organization which provides authoritative information on all aspects of foundation giving. There are dozens of regional collections of Foundation Center publications. For more information about this program or for the name of the Center's library collection nearest you, call toll free (800) 424-9836.

The Grantsmanship Center, 1031 South Grand Avenue, Los Angeles, CA 90015, is a non-profit educational institution which conducts seminars in all aspects of grantsmanship, program management and fundraising. In addition to the **Grantsmanship Center News**, they publish a comprehensive series of reprints on non-profit program management.

A foundation's own published annual report, when available, is the best single source of information about its activities. You can write to a foundation to find out if it publishes an annual report, or check the Foundation Center directories listed in the Bibliography.

BIBLIOGRAPHY

General

Broce, Thomas E. **Fund Raising: The Guide to Raising Money From Private Sources.** The Taft Group, 5125 MacArthur Blvd., N.W., Washington, D.C. 20016, 1979.

Brodsky, Jean, ed. **The Proposal Writer's Swipe File: Fourteen Professionally Written Grant Proposals.** Taft Products, Inc., 1000 Vermont Ave., Washington, DC 20005, 1981.

Flanagan, Joan. **Grass Roots Fundraising Book: How to Raise Money in Your Community.** Swallow Press, Chicago, IL, 1977. (Order from National Office, the Youth Project, 1555 Connecticut Ave., N.W., Washington, D.C. 20036., $5.75.)

Gaby, Patricia V., and Gaby, Daniel M. **Nonprofit Organization Handbook: A Guide to Fund Raising, Grants, Lobbying, Membership Building, Publicity and Public Relations.** Prentice-Hall, Inc., Englewood Cliffs, NH 07632, 1979.

Giving USA, 27th Annual Issue: A Compilation of Facts and Trends on American Philanthrophy for the Year 1981. American Association of Fund-Raising Council, Inc., 25 West 43rd Street, New York, NY 10036.

The Grantsmanship Center News. The Grantsmanship Center, 1031 South Grand Avenue, Los Angeles, CA 90015, issued six times per year.

Hill, William J. **A Comprehensive Guide to Successful Grantsmanship.** Grant Development Institute, 2140 S. Holly, Denver, CO 80222.

Kiritz, Norton J. "Program Planning and Proposal Writing", Reprinted from the **Grantsmanship Center News,** May/June, 1979. The Grantsmanship Center, 1031 S. Grand Ave., Los Angeles, CA 90015.

White, Virginia P. **Grants: How to Find Out About Them and What to Do Next.** Plenum Press, 227 West 17th Street, New York, NY 10011.

Corporations

Boyd, Tom. "The Business of Business is . . . Philanthrophy?" **The Grantsmanship Center News,** May/June, 1982, The Grantsmanship Center, 1031 S. Grand Ave., Los Angeles, CA 90015.

Brownrigg, W. Grant. **Effective Corporate Fundraising.** American Council for the Arts, 570 Seventh Avenue, New York, NY 10018, 1982.

Corporate 500: The Directory of Corporate Philanthropy. Public Management Institute, 333 Hayes Street, San Francisco, CA 94102, 1980.

The Corporate Fund Raising Directory. Public Service Materials Center, 415 Lexington Avenue, New York, NY 10017, 1980.

Dun and Bradstreet Reference Book of Corporate Managements. 13th ed. Dun and Bradstreet, Inc., 99 Church St., New York, NY 10007, 1982.

Heilman, Howard. **The Art of Winning Corporate Grants.** Vanguard Press, Inc., 424 Madison Ave., New York, NY 10017, 1980.

Koch, Frank. **The New Corporate Philanthropy: How Society and Business Can Profit.** Plenum Press, 227 W. 17th St., New York, NY 10060, 1979.

Standard and Poor's Register of Corporations, Directors, and Executives. Standard and Poor's, 25 Broadway, New York, NY 10004, 1982.

Foundations

The Bread Game: The Realities of Foundations, revised edition. Regional Young Adult Project and Pacific Change. Glide Publications, San Francisco, CA, 1982.

The Foundation Directory. 8th edition, Marianna O. Lewis, ed. The Foundation Center, 887 Seventh Avenue, New York, NY 10019, 1981.

Foundation Grants Index, Lee Noe, ed. The Foundation Center, New York, published annually in April.

Foundation News, the Foundation Center, New York, published bi-monthly.

Handicapped Funding Directory, Burton J. Eckstein, ed. Research Grant Guides, Box 357, Oceanside, NY 11572, 1982.

Kurzig, Carol M. **Foundation Fundamentals: A Guide for Grantseekers,** revised. The Foundation Center, New York, 1982. (Contains a bibliography of area foundation directors.)

National Data Book. The Foundation Center, New York, 2 volumes published annually.

1981 Foundation 500: An Index to Foundation Giving Patterns. Lawson Associates, New York. Foundation Research Service, 39 E. 51st St., New York 10022.

"Researching Foundations, Part I: How to Identify Those That May Support Your Organization," the **Grantsmanship Center News**, The Grantsmanship Center, 1031 South Grand Avenue, Los Angeles, CA 90015, 1978.

"Researching Foundations, Part II: The Big Search," the **Grantsmanship Center News**, The Grantsmanship Center, 1031 South Grand Avenue, Los Angeles, CA 90015, 1978.

Source Book Profiles. The Foundation Center, New York, annual subscription service.

Where America's Large Foundations Make Their Grants, edited by Joseph Dermer. Public Service Materials Center, 415 Lexington Ave., New York, NY 10017, 1980.

Bibliographies

"Resources for Non-Profits: A Selected Annotated Bibliography". Compiled by Philip Conley, Librarian. Associated Grantmakers of Massachusetts, Inc., 294 Washington Street, Suite 417, Boston, MA 02108.

"Sources of Information for Preparing Foundation Grant Proposals". The Foundation Center, 887 Seventh Avenue, New York, NY 10106.

"A Bibliography of Area Foundation Directories." The Foundation Center.

"A Basic Guide to Information on Foundations and Other Nonprofit Funding Sources". The Foundation Center.

An Essential Bibliography for Grassroots Consumer Organizations. Consumer Education Resource Network (CERN), 1555 Wilson Blvd., Suite 600, Rosslyn, VA 22209.

Follow-Up Assistance

If information contained in this issue stimulates further questions or a need for more in-depth information, please call or write to us at the Federation for Children with Special Needs. We will do our best to provide you with the assistance you need. Please contact:

Janet Vohs, Editor
Phone: (617) 482-2915

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COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

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FUNDING: PART II – GOVERNMENTAL SOURCES

INTRODUCTION

This issue of **Coalition Quarterly** describes funding sources through federal and state government programs that have been or could be tapped by centers operated by coalitions of parents of children with disabilities. The first article, prepared by the editor, offers general guidelines for identifying federal funding sources. A second article, written by the coordinator of the National Network of Parent Coalitions, describes two major sources of federal funds for parent coalitions: the Personnel Preparation program administered by Special Education Programs, and the Developmental Disabilities program, which has both a national discretionary funding program and a funding program that is administered in each state by a citizen planning council. A third article, prepared by the editor, lists potential state-based funding programs, and the fourth article, submitted by the director of the parent center in South Bend, Indiana, describes that center's experience with one example of state funding. This issue concludes with a glossary of terms commonly encountered in the process of securing government funds and a bibliography of additional sources of information.

Applying for government funding involves principles similar to those outlined in the articles on foundation funding in the Fall 1982 issue of **Coalition Quarterly,** "Funding: Part I, Non-Governmental Sources." Two steps, in particular, apply to all aspects of grant seeking - the need to identify those funding sources that share the applicant's concerns, and the need to tailor the request for funds to those specific priorities.

FEDERAL FUNDING

Programs to be supported by public money must be authorized by legislation and must conform to the requirements of implementing regulations. Agencies of the federal government, therefore, require detailed formal applications that meet the particular requirements of that agency's legislative authorization, regulations, and priorities. Instructions appearing in the government's application packet must be followed to the letter. Late or incomplete applications usually are automatically disqualified. Timeliness cannot be overemphasized; frequently, the receiving office literally locks the door at the time and day published as the deadline.

Applying for government funds seems formidable, and often is. What is required is a willingness to gather the necessary information and then seek out the technical assistance that is available. In addition to the publications described below, staff members at the government agencies are invaluable, willing sources of help. In addition, assistance is available through this project staff and through individual members of the National Network of Parent Coalitions.

This report was prepared under Contract No. 300-80-0859 from the U.S. Department of Education, Special Education Programs and Rehabilitative Services, Special Education Programs. Contractees undertaking such projects under government sponsorship are encouraged to express freely their judgment in professional and technical matters. Point of view or opinion, therefore, do not necessarily represent the Education Department's position or policy.

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Publication and Distribution:	**National Information Center for Handicapped Children and Youth Box 1492, Washington, D.C. 20036**

Sources of Information

The **Catalog of Federal Domestic Assistance** is a comprehensive directory of federal assistance programs. Published annually in the spring with a six-month update, the **Catalog** explains each federal domestic assistance program and helps an applicant locate units in the federal agencies which have made grants in a particular area of interest. It lists the agency and department responsible for the program, its legislative basis, the kind of assistance provided, eligibility requirements, application and award procedures, and applicable regulations and guidelines. It also identifies a person to contact for more information and refers to related programs.

Once a promising program has been located, a grant application packet should be requested from the contact person, by telephone to save time. The contact person will be happy to answer questions after the application packet has been reviewed, while the application is being prepared. This personal assistance has proven to be invaluable to parent coalitions, not only in developing their applications, but also in implementing the projects after funding has been secured. Generally, contact persons will provide information and assistance on questions of procedure arising from the packet; after the competition(s) have been announced in the **Federal Register,** to ensure fairness to all applicants, contact persons cannot comment on the quality of ideas to be proposed in the application.

Two daily publications update the **Catalog** with information about new programs and important program changes. The **Federal Register** gives current information on grant programs, including application procedures and deadlines. **Commerce Business Daily** lists all contracts that the federal agencies plan to award.

The **United States Government Manual** is another source of information that can be used in tracking down federal programs. It lists U.S. Government agencies, their programs, and key officials.

The above publications can be ordered from the U.S. Government Printing Office, c/o Superintendent of Documents, Washington, D.C. 20402. They are also available in state law libraries, libraries of major universities or colleges, depository libraries in each congressional district, Regional Foundation Center Libraries, and most public libraries. For the nearest Foundation Center Library, call (800)424-9836.

Another helpful resource is the Federal Assistance Programs Retrieval System (FAPRS), a computer-based information program of sources of federal funds that is maintained by the Office of Management and Budget. FAPRS is largely based on the information contained in the **Catalog**, but it is updated much more frequently. An information packet on FAPRS, which includes a list of access points in various cities, is available from: Federal Program Information Branch, Office of Management and Budget, 726 Jackson Place, NW, Washington, D.C., 20503.

Grants and Contracts

The federal government disburses funds directly to organizations either through grants or through contracts. It is important to be aware of the differences between the two funding mechanisms because they influence certain aspects of the proposal (submitted for contracts) or the application (submitted for grants) as well as the manner in which recipients must manage the funds once they are awarded.

In a **contract**, the government buys something it wants. The government states exactly what it wants done and lays out the specific tasks and timelines required to meet a need or solve a problem as it is perceived by the government. Contracts require an end **product**. For instance, the government might solicit bids for a contract to produce 40,000 ball bearings to be used for 1,000 pairs of roller skates, to be delivered by December 1, 1983. Normally, the lowest dollar amount in the timeframe alloted wins the contract.

Grant programs, on the other hand, are the government's efforts to respond to needs that are identified by specialists outside the government. The agency applying for funds develops the specific ways to meet the need or solve the problem and the government agrees to assist the applicant agency with meeting the need. A grant is often described as a "conditional gift" in which there is no requirement to produce, but rather a requirement to **perform** in accordance with the terms and conditions of the grant. The recipient agency puts forth a "best effort" to meet the goals and objectives that have been established.

For example, in response to the needs expressed, the government might solicit grant applications for demonstration projects designed to increase mainstreamed recreational opportunities for children with special needs. Applicants are free to propose their own methodology, their own ideas, about how to meet the need. One organization may propose to train volunteers to assist children with special needs at public roller-

skating rinks or to set up a big brother/big sister program focusing on learning, recreational, and training experiences that might include roller skating, bowling, movies and field trips. Another organization may propose to train the operators of skating rinks and bowling alleys to be sensitive to the needs of handicapped children.

Following are some other important differences between grants and contracts:

Contracts

- Proposals for contracts are generally due 30 days after the request for proposal (RFP) has been announced and bids solicited.
- RFPs for contracts are announced in the **Commerce Business Daily.**
- The award process for contracts is usually faster than that for grants.
- While preparing a proposal for a contract, the applicant may communicate only with the contracts office staff responsible for the fiscal management of the project.
- Contract proposals do not have to justify need because the contracting agency has already established the need.
- Contract proposals usually do not include letters of support.
- Contents of the proposal for a contract are specified by the government in the RFP.

Grants

- Timelines for grant applications vary widely, sometimes as long as 90 days.
- Applications for federal grant programs are announced in the **Federal Register.**
- Grants can take as long as six months from application deadline to award notice.
- While preparing a grant application, applicants may discuss the project with the program office staff of the funding agency, as well as the grants officer.
- Justification of need is an important part of grant applications.
- Grant applications usually include letters of support.
- Grant applications give more freedom and flexibility to the applicant in designing the program.

MAJOR SOURCES OF FEDERAL FUNDS FOR PARENT CENTERS

Martha Ziegler, Coordinator, National Network of Parent Coalitions

Training Grants, Division of Personnel Preparation

During the last six years, coalitions of parents of children with disabilities have relied heavily on training grants through the Division of Personnel Preparation (DPP), Special Education Programs (SEP), U.S. Department of Education, for the basic funds required to operate information and training centers. Recently, the department has revised the DPP regulations in a way that should facilitate greater access to these funds by parent coalitions. Instead of competing in the same pool with universities and professional organizations submitting grants for teacher training programs, as in the past, parent coalitions will now compete in a separate categories for training of parents and volunteers only.

The overall requirements and format for these grants remain the same as before:

1. Careful documentation of the need for the training project, including reference to the training priorities in the training section of the state's plan for implementing P.L. 94-142.
2. Relationship of the planned program to the educational needs of handicapped children.
3. A well designed plan of implementation of the project, including clear objectives and the planned use of personnel and other resources.
4. Detailed description of the program content, including the competencies to be achieved by the trainees and the methods, procedures, techniques, and instructional media and materials to be employed.
5. A plan for evaluating the effect of the training program.
6. An evaluation design.
7. Qualifications of the project director and the other key personnel and indication of non-discriminatory employment practices.
8. Adequacy of the resources (facilities, equipment, and supplies) to be used for the program.
9. Contributions of time, expertise, money, and goods from sources other than the grant.
10. Itemization of budget, budget explanation, justification, and demonstration of reasonableness, adequacy, and cost effectiveness of the proposed budget.

Each fiscal year, Congress appropriates money for this program (Training Personnel for the Education of the Handicapped) as one of several discretionary programs to be implemented by SEP on a nationwide basis. For the current funding period, 49.3 million dollars has been allocated by Congress for Personnel Preparation. As of this writing, a similar total is anticipated for the next funding year; of this total, approximately $3.5 million has been earmarked by SEP for training parents and volunteers each year.

Grants under DPP are awarded annually and they must meet stringent requirements that are described in an official packet, "New Application for Grants Under Training Personnel for the Education of the Handicapped," available free of charge from the Division of Personnel Preparation, U S. Department of Education, Special Education Projects, Washington, D.C., 20202. Usually, this booklet is published in August and new grant applications are due by a well-publicized date in October or November. (In 1982-83 the deadline was postponed until January 21, 1983, because of a delay in promulgating the revised regulations for the program.) An applicant must secure a copy of the official application packet and follow the instructions meticulously in preparing the grant application.

Criteria to be used by the panel of reviewers when reading the application are described in the application packet. It is wise to make certain that each question is answered, even though the response may appear to be "not applicable."

Staff members of DPP have been very helpful to parent coalitions when they have decided to submit applications under this program. In addition, as coordinator of the National Network of Parent Coalitions, technical assistance (though not proposal writing) is available through the Federation for Children with Special Needs.

Developmental Disabilities Grant Program

The second source of government funds most attractive to parent coalitions is the money allocated through the Developmental Disabilities Program, a division of Vocational Rehabilitation. A relatively small amount of money is awarded through grants at the national level; these are announced annually in the **Federal Register,** with a description of the DD agency's funding priorities for the year. A larger amount of DD money is distributed in each state, through the DD planning council for the state. Several parent coalitions have supplemented their activities with state DD grants. The Federation for Children with Special Needs, for example, is now implementing its second DD grant to train lay persons to represent developmentally disabled people or their families in administrative hearings. A parent coalition needs to be in touch with the state DD Council to keep current on the availability of these funds.

Parent centers have occasionally found federal funds in unexpected programs. The Coordinating Council for Handicapped Children, Chicago, Illinois, is implementing a grant from the Office of Juvenile Justice and Delinquency Prevention, U.S. Department of Justice, to run a delinquency prevention program focusing on advocacy, peer support and counseling, and awareness activities in the public schools.

STATE FUNDING

State departments of education, health, mental health, welfare, juvenile justice, and others are all potential sources of funding for the work of parent coalitions. Several centers have secured state department of education grants to run projects for surrogate parents, prepare booklets on special education for parents, help conduct the state's child find activities, and operate advocacy programs for adjudicated and incarcerated youths with handicaps.

It is important to be familiar with the state plans required under certain federal programs, because these are likely to highlight the state's own priorities, which may well mesh with the goals of the parent coalition. P.L. 94-142, for example, requires that each state implement a Comprehensive System of Personnel Development (CSPD) as part of the state plan. If the State Educational Agency has included parent training as one of the priorities in the plan for personnel development, the parent coalition will want to assist the SEA in implementing that priority, either by applying for SEA funds or by referring to this priority of the state plan when applying for federal training funds, as required in DPP applications.

Experienced parent centers have learned that it is worthwhile to be on the mailing list for grant announcements for each of the education and human services agencies in the state.

The following article illustrates how one parent center succeeded in identifying a state need and then helped the State Department of Education implement a program.

ONE CENTER'S EXPERIENCE

Sally Hamburg, Director, Task Force on Education for the Handicapped

Following the passage of P.L. 94-142, the Task Force on Education for the Handicapped, a parent center in South Bend, Indiana, approached Indiana's Director of the Division of Special Education and offered to research the surrogate parent provision of P.L. 94-142 and to design a plan for implementing it in Indiana. A Task Force volunteer studied the provision and wrote a proposal for a pilot project that would establish surrogate parent programs in South Bend and the surrounding school districts.

The Division accepted this proposal, with minor revisions, and, in 1977, established the Indiana Surrogate Parent Program, to be administered by the Task Force. Following the completion of the pilot project in 1978, the Division approved the project on a statewide basis. Surrogate Parent Program staff provide information and assistance to local school districts and other education providers in training and assigning surrogate parents. At least 75 percent of each state's funding allotment under Part B, Education of the Handicapped Act, goes to Local Education Agencies (LEAs) who submit applications for these funds. The remainder of the Part B funds is used by the State Education Agency (SEA) for administration of the Act and for discretionary programs, such as the Surrogate Parent Program.

The success of the Task Force in obtaining funding from the SEA can be attributed to a combination of the following factors:

- **Timing** — The first Director of the Task Force thoroughly examined the regulations for P.L. 94-142 prior to its actual implementation, noted the surrogate parent requirement (for which no states had as yet developed policies or programs), and immediately approached the SEA with the idea of designing a plan for fulfilling the requirements of that provision.
- **SEA Administrative Responsibilities** — The SEA's Division of Special Education had insufficient administrative personnel to devote the person-hours necessary to research fully the provision and design a program that could be quickly developed for use by LEAs.
- **Credibility of the Task Force** — The Task Force, begun as a volunteer organization in 1973, had developed a working relationship with administrative personnel in both the LEA in South Bend and the SEA in Indianapolis. The Task Force volunteers, many of whom later became staff members, were well informed parents who had been involved in parent advocacy groups and had demonstrated their ability to work as partners with professionals to achieve quality services for handicapped children. The Task Force further established its credibility when it was awarded a contract by the then Bureau of Education for the Handicapped in 1976 to set up one of the original five Parent Information Center.
- **Comprehensive And Realistic Planning** — The Task Force's 1977 Surrogate Parent proposal was comprehensive but realistic in scope. Our original pilot program would serve as a model to determine how statewide policies and procedures could be established.
- **Demonstrated Success** — During the pilot project, staff demonstrated the ability to complete the project's objectives.
- **Need for Compliance with P.L. 94-142** — The Task Force, in administering the Surrogate Parent Program in Indiana, was helping the SEA to comply with the law. The Task Force, under contract to the Indiana Department of Public Instruction, Division of Special Education, has administered the Surrogate Parent program since its inception. Through the Indiana Surrogate Parent Program, the Task Force assists public agencies to develop and implement local surrogate parent programs. For 1982-83, the State Surrogate Parent Office has been funded by the SEA to prepare additional materials for parents and LEA personnel on topics related to parent involvement.

Establishing a working relationship with the SEA and demonstrating an ability to accomplish the work effectively and efficiently were essential ingredients to the Task Force's success in obtaining SEA funding.

GLOSSARY

Authorizing Legislation — A law that creates a federal program and defines what type of program is set up, who will run it, and how the program will operate.

CBD — **Commerce Business Daily.** (Announces federal contracts up for bid).

CFDA — **Catalog of Federal Domestic Assistance**

CFR — **Code of Federal Regulations**

Contracts Officer/Grants Officer — The federal person primarily responsible for the fiscal management of project grants and contracts. This individual is ultimately responsible for all aspects of a federally issued grant or contract.

CSPD — Comprehensive System of Personnel Development (State Plan)
DPP — Division of Personnel Preparation (U.S. Department of Education, Special Education Programs)

ED — Department of Education

EDGAR — Education Department General Administrative Regulations

FAPRS — Federal Assistance Program and Retrieval System

FR — **Federal Register.** (Announces federal grant programs).

LEA — Local Educational Agency

OHI — Office for Handicapped Individuals (U.S. Department of Education)

OMB — Office of Management and Budget

Project Grants — Discretionary funding given out by federal agencies through competitive grant awards for specific projects over fixed periods of time.

Project Officer — Federal person responsible for the technical programmatic management of project grants and contracts.

Regulation — Once legislation authorizing a program is passed, officials in the administering agency develop rules that spell out exactly how a program will operate. (Regulations are found in the **Code of Federal Regulations** and the new regulations are announced in the **Federal Register).**

RFP — Request for Proposal, used for federal contracts.

SEA — State Educational Agency

SEP — Special Education Programs, section of U.S. Department of Education.

BIBLIOGRAPHY

"An Inside Look at How the Government Evaluates Proposals," **Grantsmanship Center News** Reprint Series, 1015 W. Olympic Blvd., Los Angeles, CA 90015.

Catalog of Federal Domestic Assistance, Office of Management and Budget. GPO, C/0 Superintendent of Documents, Washington, D.C. 20402. $30.00, published annually.

Commerce Business Daily, U.S. Department of Commerce, GPO, Superintendent of Documents, Washington, D.C. 20402. $100/yr., published daily.

Des Marais, Philip. **How to Get Government Grants.** Public Service Materials Center, 415 Lexington Avenue, New York, N.Y. 1975.

Department of Education Weekly. Feistritzer Publications, 1261 National Press Building, Washington, D.C. 20045. $224/yr.

Federal Register, National Archives and Records Service, General Services Administration. Order through GPO, c/o Superintendent of Documents, Washington, D.C. 20402. $300. (Published daily).

Handicapped Funding Directory, 1982-83. Burton J. Eckstein, editor. Research Grant Guides, P.O. Box 357, Oceanside, N.Y. 11572. 1982.

1982 Guide: U.S. Department of Education Programs, Parts I and II. Government Printing Office, c/o Superintendent of Documents, Washington, D.C. 20402. Published annually.

Programs for the Handicapped, Office for Handicapped Individuals. GPO, c/o Superintendent of Documents, Washington, D.C. 20402. Monthly, no cost.

U.S. Government Manual, Government Printing Office, c/o Superintendent of Documents, Washington, D.C. 20402. Published annually.

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COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

Volume III, Number 1 *Spring, 1983*

MANAGEMENT GUIDE FOR THE RELUCTANT ADMINISTRATOR

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INTRODUCTION

Previous issues of ***Coalition Quarterly*** have addressed such management concerns as organizational and program development, and have provided information on funding sources and procedures for acquiring funds. This issue is devoted to ensuring that funds received will be properly managed. Both private and public agencies require that recipients of funds meet certain standards of accountability which include providing relevant and adequate documentation of their activities and expenditures. This issue focuses on federal government standards since they are generally more stringent than requirements of private funding organizations. State government standards are similar to federal ones, but since they can vary in detail, the particular state requirements should be studied carefully. Even recipients of federal funds should be careful to check the requirements of their current funding agencies, since specific requirements may well vary from agency to agency, and program to program.

Some more words of caution. Many of the published operating procedures for managing federal money that apply to grants and contracts disbursed by the Department of Education were initially issues when education was still part of the Department of Health, Education and Welfare (DHEW). It should not be assumed that publications are irrelevant or out-of-date simply because they have not been reprinted by the Department of Education. If the contracts or grants officer sends written procedures to a recipient organization, it is safe to assume that the information is still current. There are several key documents with which recipients of federal funds should be familiar: standard information that accompanies each award notification; **Education Department General Administrative Regulations** (EDGAR)[1], for Department of Education grants; "General Provisions for Negotiated Cost-

[1] Now codified in Title 34 of the **Code of Federal Regulations**, Parts 74, 75, and 76 as "Education Department General Administrative Regulations". "Part 100 a" is redesignated as Part 75, and "Part 100 b" is redesignated as Part 76.

This report was prepared under Contract No. 300-80-0859 from the U.S. Department of Education, Special Education Programs and Rehabilitative Services, Special Education Programs. Contractees undertaking such projects under government sponsorship are encouraged to express freely their judgment in professional and technical matters. Point of view or opinion, therefore, do not necessarily represent the Education Department's position or policy.

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Reimbursement Type Contracts with Nonprofit Institutions Other than Educational Institutions," for contracts management; and **Standards for Audit of Governmental Organizations, Programs, Activities, and Functions**, written by the Comptroller General of the United States.

The first article, prepared by the editor, is based on a talk given by Mr. Kenneth Franks, Jr., Chief, Business Management Branch, U.S. Department of Education. It addresses common difficulties that newly funded organizations encounter when they must quickly learn to implement unfamiliar administrative and procedural requirements. The next article, prepared by Martha H. Ziegler, Executive Director of the Federation for Children with Special Needs, discusses the role of documentation and internal control in funds management. The final article, by Martha Gentili, Director of the parent center in Tacoma, Washington, lists suggestions and recommendations from her vantage point as director of a program recently funded for the first time. A bibliography of basic references concludes this issue.

ADVICE FROM A PRO

This article summarizes some of the advice given in training workshops conducted by Mr. Kenneth Franks, Jr., who is Chief of the Business Management Branch, U.S. Department of Education. Much of this information was transcribed from a speech given by him at the annual conference of the National Network of Parent Coalitions held in Washington, D.C., February 1983. Mr. Franks was kind enough to supply additional information for this article.

A key message conveyed by Mr. Franks is the following: "No matter how you may view yourself—as someone totally committed to improving the lives of handicapped children, for example—the moment you become the director of a federally funded project, you must completely revise this image of yourself; suddenly you must view yourself *first* as a manager and administrator, and second as a concerned, knowledgeable program director." The difficulty arises because most program directors, including those who head centers operated by coalitions of parents of children with disabilities, rise to leadership positions primarily because of their expertise in program areas, not because they have formal training as administrators or managers. Furthermore, the grant applications and the review panels often place more emphasis on programmatic than on administrative expertise.

Luckily, the federal government has available a variety of resources to help the newly funded program director make the psychological shift. In addition to such professional staff as grant and contract officers who are only a phone call away, the government has several publications that can be added to the library shelf for instant reference *following initial study*. These documents are listed in the bibliography on page five and they are referred to throughout the text of this issue.

In the course of making that mental shift from program expert to manager, another tip from Mr. Franks appears facetious but may prove to be very helpful; he suggests that project directors cultivate a high degree of "professional paranoia," supplemented with simple common logic and with some hard information. In applying the "paranoia" recommendation, one parent center director suggests that the newly funded project staff should assume, at the outset, that there will be a government audit, beginning tomorrow. Mr. Franks agrees that running a project on the assumption that there will be an audit is one of the best ways to guarantee good management.

One key requirement for proper management of funds is documentation. Mr. Franks indicates that on the basis of his own professional experience with federal audits, the following three areas have caused the most problems and are the source of most criticism by auditors:

> **1. Contemporaneous evidence to support monies paid to project staff.** A staff timekeeping procedure must be established to verify that each employee did, in fact, work the time stated on that particular project. The supervisor and employee are responsible for indicating the actual hours worked, so that the amount paid an employee can be traced to signed documents. "Contemporaneous" means that the time sheets were filled out within a reasonable time after the completion of each week's work, not filled out all at once a year or more later. Many a project has discovered to its chagrin how easy it is for an experienced auditor to detect the fact that documentation has been recorded long after the fact.

2. Quality of evidence that consultants have been paid for actual work performed. Procedures for employing and paying consultants are more complicated than those for project staff. An organization must follow required procedures for obtaining and documenting consultant services. Consultants can only be hired when there is no way for existing staff members to do the job, either because of time limitations or lack of qualifications for the task. In some circumstances, at least three bids must be solicited before a consultant is hired. A call to the contract or grant officer will answer this question. If such bids are needed, they should be recorded and filed.

Once a consultant has been selected and approved, a contract with that person must be drawn up that will answer the following questions: Who? What? When? Where? Why? How? How much? The contract should indicate whether the fee is all inclusive or whether per diem, travel, or other expenses will be paid separately. If some expenses are to be paid separately, each item should be listed. In order to receive payment, the consultant should submit an invoice that specifies the time, dates and tasks performed. Probably the most important item needed is some evidence that the consultant did produce something. The fact should be noted here that the consultant is under a contract and a contract requires an end *product*, rather than a demonstrated best effort, as required by a grant. The product need not be elaborate; a written report, or an outline of a presentation, for instance, will demonstrate that the consultant did indeed complete the task as agreed.

3. Adequate support documentation for travel. Documentation supporting the *reason* for the travel, as authorized by the grant or contract, must be included in the permanent file. These records might include such items as a copy of the agenda or printed program that includes the traveler's participation, or correspondence about the type of assistance or participation provided. In addition, receipts must be submitted as part of the documentation file before payment is final.

From his perspective as one of the people charged with final decisions on audit findings, Mr. Franks likes to end his training workshops with the following advice: "Immediately read and reread the few pages of fine print that accompany your grant or contract award, *or* be prepared to pay me later."

ADVOCACY SKILLS AND GRANT MANAGEMENT

Martha H. Ziegler, Executive Director
Federation for Children with Special Needs

In the same way that a carefully developed evaluation plan can be an invaluable tool for framing objectives and periodically revising a program, the standards for a federal audit can be used internally as a model for initiating and periodically reviewing the management practices of an organization.

In one sense, federal audit standards are merely a systematic way of guaranteeing that the taxpayers' money is expended legally, with adequate economy and efficiency, and in a manner that produces the program results agreed upon in the contract or grant that has been awarded. In other words, parents of children with disabilities might view the federal audit as a tool for helping to insure that tax dollars will be spent according to law and regulations in order to serve a maximum number of handicapped children and their families in a program that produces optimal benefits for those being served. Therefore, parent centers might well apply some of the advocacy techniques to their own operations in order to assure responsible management. Such competencies as knowledge of relevant laws and regulations, and skills of timely documentation apply as much to grant and contract management as they do to securing an appropriate educational program for a handicapped child.

The basic textbook for management of federally funded programs is a government publication called **Standards for Audit of Governmental Organizations, Programs, and Functions**, by the Comptroller General of the United States, 1981 revision. This booklet, clearly written in jargon-free English, should be required reading for managers of government funds, especially beginners. It clearly explains several terms that are often used loosely and imprecisely. The book describes the standards and scope of audit work in such clear, inexorable steps that sound management practices assume a logical necessity. Once a manager digests this book, it should be nearly impossible to return to any earlier sloppy habits.

Two frequently heard, dimly understood terms, "audit trail" and "internal control," take on clear meaning and importance in the context of the Comptroller General's discussion of audit standards. The "Yellow Book," as it is called by insiders, explains "audit trail" as the written record of transactions that document a system of internal control. Systems must be designed and implemented that will enable an auditor to trace a transaction (rental of a typewriter, for example) from its initiation (a purchase order with an authorizing signature), through all the intermediate processing steps (written bids from several sources, for instance), to the resulting financial statements (inclusion of the cost of typewriter rental in the voucher to the funding agency and in the cumulative total of expenditures in the appropriate line item). Conversely, information included in the financial statement must be readily traceable to its origin. In other words, it must be possible for an auditor to track down each transaction that has gone into the total expenditures for a particular item (equipment rental, in this example) and be able to verify that each transaction had been properly authorized and concluded. Such a trail provides evidence that the rental of the typewriter was a careful, legal, properly authorized use of funds necessary for the operation of the program.

The important element of documentation in an audit trail is the record of authorization, giving evidence of "internal control." Internal control includes both administrative control and accounting control, and both are systems for documenting the ways in which decisions are made to achieve the objectives of the organization and to safeguard the organization's assets. In addition to providing an audit trail, internal control will guarantee that "access to assets is permitted only in accordance with management's authorization."[2] For a parent coalition managing a federal grant, this control means that the organization operates an internal management system that assigns to a certain person, and only that person (usually the project director), the authority to make decisions about the use of the money disbursed through the grant. The audit trail will constitute written documentation of the use of that authority in each step of each transaction, whether purchase of pencils, payment of rent for office space, or weekly issuance of payroll checks. Thus proper internal control and a good audit trail serve to protect the organization and its employees as well as to safeguard the use of public money.

TIPS FROM A BEGINNER

Martha Gentili, Director
PAVE, Tacoma, Washington

Following are some suggestions I wish we had had when we began to implement our training grant:

1. Hire a bookkeeper who has some familiarity with federal grants and contracts.
2. Start at the very beginning with a good bookkeeping system. A "one-write" system, which provides carbon copies of each check on the register, is a sensible way to prevent copying errors.
3. Be willing to ask your grants officer for an explanation of *anything* you do not understand. No matter how foolish you may think your question is, you can rest assured that the grants officer has heard plenty of questions equally foolish.
4. Obtain sample copies of completed government forms (for example, the 990, cash request, cash summaries, budgets) from another project with experience.
5. Obtain sample copies of forms for internal control (purchase orders, travel authorization, consultant contracts, for example) from other more experienced parent centers. (***Coalition Quarterly*** will help you secure these sample forms.)
6. Set up a schedule for periodic review of your expenditures versus your approved budget allocations and try to identify serious over or under expenditures. This review should occur at least quarterly. If at any point the discrepancy appears to be so great that you think your original budget should be revised, consult with your grants officer for advice.

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[2] Statts, Elmer B., Comptroller General of the United States, **Standards for Audit of Governmental Organizations, Programs, Activities, and Functions**, U.S. Government Printing Office, Stock #020-000-00205-1, Revised, 1981, page 68.

7. Plan your budget so that you can include an annual certified audit by a private auditing firm, preferably one that has experience with federal funds and with nonprofit agencies.

8. One person should be designated to approve expenditures before the actual expense is incurred.

9. Know your restrictions upfront, especially with regard to overhead allowances and limitations on fringe benefits.

BIBLIOGRAPHY

"Education Department General Administrative Regulations" (EDGAR) **Code of Federal Regulations,** Parts 74, 75, 76 & 77, 1 July 1982, as amended by Vol 47. **Federal Register,** p. 31382, July 20, 1982

"General Provisions for Negotiated Cost-Reimbursement Type Contract with Nonprofit Institutions other than Educational Institutions," U.S. Department of Health, Education and Welfare, document #315A, revised July, 1976. Available through the Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

"The New Contractsmanship," Keith Baker, reprinted from the **Grantsmanship Center News,** 1031 South Grand Avenue, Los Angeles, CA 90015, 1976.

Statts, Elmer B., Comptroller General of the United States, **Standards for Audit of Governmental Organizations, Programs, Activities, and Functions.** Available through the Superintendent of Documents, Stock #020-000-00205-1, 1981 Revision, $4.75.

Other U.S. Government pamphlets supplementing the standards for audit have been issued which may prove helpful:

"Examples of Findings from Governmental Audits," Stock #020-000-00115-1

"Questions and Answers on the Standards for Audit of Governmental Organizations, Programs, Activities and Functions," Stock #020-000-00145-3

"Using Auditing to Improve Efficiency and Economy," Stock #020-000-00133-0

"Using Broad Scope Auditing to Serve Management," Stock #020-000-00155-1

The above pamphlets are for sale by the Superintendent of Documents, Public Documents Department, U.S. Government Printing Office, Washington, D.C., 20402

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Dear Reader,

Your input is important to us! In order to supply you with the information you need, we need to hear from you. Let us know if you have found the ***Coalition Quarterly*** helpful and how you have used it. If there are any topics you would particularly appreciate being covered, please let us know that, too. The more responses we receive, the better we can suit the information to your needs.

Also, if information contained in any of the issues stimulated further questions or a need for more in-depth information, please call or write to us at the Federation. We will do our best to provide you with the assistance you need. Contact:

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COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

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VOLUNTEERS IN THE PARENT CENTER: AN ESSENTIAL PARTNERSHIP

Volunteer work is integral to the operation of many organizations serving people with disabilities. Parent coalitions, in particular, began with the volunteer efforts of parents to secure educational rights for their children with disabilities. Now, many parent coalitions operate centers with paid staff members who have been hired from the ranks of the original volunteers. Centers continue to rely on volunteers, both as a way to expand the services that the centers can offer, and to empower and inform parents and others who volunteer. Therefore, volunteer programs in the parent center can be seen as a service *for* the center and as a service offered *by* the center.

The reciprocal nature of volunteering in the parent center offers an opportunity for a powerful, dynamic partnership. This issue of ***Coalition Quarterly*** describes some current volunteer programs and highlights some principles that have proven to be valuable in creating and sustaining that partnership.

VOLUNTEER RESOURCES

There is no single program model for volunteer participation in parent centers. Each center has its own way of integrating volunteer efforts into the total fabric of its own program goals and objectives. Volunteers have been drawn from the ranks of retired citizens, parents of children with special needs, CETA workers, university students (both graduate and undergraduate), disabled adults and adolescents, friends and neighbors, and professional persons in the community.

Often these volunteer resources grow from informal contacts to long-term, formal arrangements. For example, one parent center, located near several colleges and universities, informally encouraged interested college students to use the center's library for research projects or term papers which would be mutually beneficial to the student and the center. Gradually this arrangement became formalized into written job descriptions being submitted to a central student placement office. The students could gain academic credit for the supervised work they did at the parent center, and the parent center provided resources that the students would not otherwise have had access to. A sampling of student projects includes performing legislative research, updating printed material, organizing library materials, compiling up-to-date directories, editing the newsletter, and assisting with training projects.

In another instance, a parent center found itself located in the same building, just down the hall, from a vocational training program for adults with developmental disabilities. It was not long before an informal arrangement was set up whereby the adults in the workshop did many of the routine clerical tasks, like stapling, collating, and photocopying, as part of their training. The entire staff of the parent center became friendly with the workshop participants and gave them much appreciation and praise for the work they did. The volunteers provided a valuable service and were delighted to have helped in a "real-office" situation; without this assignment they had to practice with "pretend work."

This report was prepared under Contract No. 300-80-0859 from the U.S. Department of Education, Special Education Programs and Rehabilitative Services, Special Education Programs. Contractees undertaking such projects under government sponsorship are encouraged to express freely their judgment in professional and technical matters. Point of view or opinion, therefore, do not necessarily represent the Education Department's position or policy.

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A number of centers report that senior citizen volunteers are especially loyal and reliable. They are motivated almost exclusively by a desire to be of service, to make a difference in the lives of other people, especially children, and to feel needed.

Coalitions have also benefited from professional advice and assistance from lawyers, accountants, public relations and publicity experts, business managers, journalists and teachers. Many centers are able to attract professionals to donate time. Others recruit specific needed professional help from programs like United Way's "Management Assistance Program" (MAP).

Parents as Volunteers

Parents of children with special needs who have received assistance from the parent center have always been a valuable volunteer resource. Often parents receive the assistance they need through special workshops designed to inform them of their rights and responsibilities under various laws.* As a logical extension of the standard parent training, centers are now training key parents in specified geographical regions to provide assistance and training to other parents in their communities.

One such program, the Indiana Parent Training Program (IPTP), conducted by the Task Force on Education for the Handicapped, Inc., in South Bend, Indiana, trains parents to serve as Regional Parent Representatives (RPRs).** Joan Miltenberger, Project Coordinator, shared some of the conclusions of the IPTP staff: "We have begun to realize that the parent advocates we train are truly volunteers 'in the field.' We have made an effort *not* to coddle our volunteers, but have presented them with the challenge of helping other parents develop skills to work as equal partners with the schools. Though they are not paid staff, their commitment to the organization must be strong and the organization's support to them must be consistent."

Knowledgeable, experienced parents are recruited from among participants in the basic workshops for parents, from special education advisory boards, parent groups, and are referred by special education personnel. They are offered the opportunity to conduct training themselves for other parents in their community. Applicants are required to complete a questionnaire designed to assess their specific areas of interest, their knowledge of special education laws, and their level of commitment to parent involvement and to promoting cooperative school-home relationships. Once the RPRs have been selected and their needs determined, the IPTP staff trainers clarify their training goals and spell out the responsibilities of the staff and the RPR through further interviews.

The RPR's participate in an initial, intensive two-day training session, designed to meet the following objectives:

- to convey in-depth knowledge of federal and state legislation, the special education process and community resources,
- to help trainees develop their skills in interviewing and problem-solving, communicating with school personnel and in conducting workshops for groups of parents and professionals.

In a follow-up training, participants learn to conduct an informal assessment of parent education/information needs and to determine how they, each with their different skills, will carry out parent education efforts.

Joan Miltenberger stresses the importance of ongoing follow-up support from the training staff: "As a volunteer or staff person our greatest motivation and rewards are often personal and intrinsic. We need to continue to help the RPR develop motivation and skills through ongoing feedback, professional development opportunites and recognition."

In a similar program conducted by the Parent Educational Advocacy Training Center in Alexandria, Virginia, directed by Winifred Anderson, three-member Parent/Professional Teams are prepared to work together as volunteers. The Parent/Professional Teams work in their respective communities to teach parents the knowledge and skills needed to be effective educational planners for their children with disabilities. Each team consists of at least one parent of a child with special needs and at least one professional currently working in the field of special education.

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* This type of parent training was discussed in a previous issue of *Coalition Quarterly*, "Advocacy Management in the Parent Center," (Volume I, Numbers 4 and 5).

** This training program is covered in more detail in *Counterpoint*, Vol. III, Number 2, Nov. 1982, in an article entitled "Indiana Parent Training Program," by Joan Miltenberger, pg. 19.

During an intensive four-day workshop held at a conference center, the Parent/Professional Teams learn the substantive content necessary to conduct parent training workshops covering all phases of the educational cycle. The basic training materials for the workshop include:

1. *Negotiating the Special Education Maze: A Guide for Parents and Teachers*, written by parent center staff members Winifred Anderson, Stephen Chitwood, and Deidre Hayden, published by Prentice/Hall, Inc. in 1982;
2. State regulations governing special education programs;
3. *Mastering the Maze*, a training manual for Parent/Professional Teams.

In addition to the information needed to conduct parent trainings in their communities, the team members learn management principles relating to shared leadership. The volunteer trainees must learn how to become team leaders, to recognize their own and each other's strengths and weaknesses, and determine how they can best work together. By the time the team leaves the four-day training program, it has developed a management plan which spells out specifically which team member is responsible for each aspect of the parent training courses they will conduct in their community.

Following the Parent/Professional Team training workshop, each team is required within the following six months to conduct at least two fifteen-hour workshops for parents. The content of the parent workshop includes child development topics in which parents learn to document their personal information about their child and to use this information effectively in school meetings. Skills in "record decoding" are taught which provide parents a technique for interpreting and using their child's school records. Information and training concerning the local school system's process for identification, evaluation, eligibility, Individualized Education Programs, placement, annual review and due process procedures are included in the content for parent training courses conducted by the Parent/Professional Teams.

Ongoing support and technical assistance constitute an important part of the services provided to the volunteer teams by the parent center staff. Each team has a parent center staff member assigned for this purpose. The staff person attends the team's first training course in the community, offers constructive feedback, and serves as a contact person for ongoing supervision. A regular newsletter keeps the team members up-to-date and serves as a forum for the volunteers to share new techniques, solutions, and successes. Follow-on inservice training workshops highlight one aspect of the job the volunteers are required to do in the community. Teams are provided time to plan modifications to the training courses they conduct in order to allow for the uniqueness of each local school system. The opportunity to modify the training course design and to adapt the program to their own community is intrinsically rewarding to the volunteer trainers.

Other centers have designed programs to train parents and professionals to represent people with disabilities or their parents at due process hearings. In exchange for the training, and as part of their practicum requirement to receive a certificate of completion, participants agree to volunteer a specified amount of time or handle a specified number of cases.

Management Strategies

The following are some additional reminders and cautions based upon parent center experiences in managing volunteer programs:

Commitment of Management. This commmitment implies that the leadership of the organization has thought carefully about the role of the volunteer in the overall program, and has allotted the necessary resources, both in terms of staff hours needed for supervision and training, and, if possible, for stipends to cover volunteer expenses. To assure that staff at all levels do their part to make the volunteer program work, it is important that they be involved in the design of the program from the beginning.

Status of Volunteer. It is important that the volunteers know the relationship of their job to the overall effort, and that the goals and objectives for the volunteer programs are inseparably linked with those of the agency. The volunteer's commitment to the job is as serious as that of a paid worker. Written job descriptions should clarify *specific* duties and timelines, and a supervisor should be assigned. In addition to job descriptions, the Southwestern Ohio Coalition For Handicapped Children, Cincinnati, Ohio, has designed a "Memorandum of Understanding" which spells out *overall* volunteer/agency relationships and responsibilities.*

* Sample available through the ***Coalition Quarterly*** or directly through Southwestern Ohio Coalition For Persons with Disabilities, 3333 Vine Street, Cincinnati, Ohio 45220.

Supervision. Volunteers should receive initial training and orientation comparable to that provided paid staff. Betty Hourihan, Director of VIA, Volunteer Information Agency, Quincy, Massachusetts, stresses the importance of staying closely involved with the volunteer during the start-up time. At the same time, she stresses being sensitive to the moment when the volunteer is ready to do the job without direct supervision. Inservice training should also be given to the staff in supervising volunteers.

Confidentiality. Volunteers should have access to confidential files as needed to carry out their job responsibilities. They should be trained and supervised by the staff to use the records appropriately, and should be expected to honor the same standards of confidentiality as salaried employees.

Records. Documentation of individual volunteer service should contain information on the type of assignment given, work performed, hours served, time sheets, evaluations, and references. Thorough records of the volunteer activities comparing the value of services provided in return for dollars invested will also demonstrate cost effectiveness.

VOLUNTEERS THAT WORK

Elizabeth Binkard, Marge Goldberg, and Paula Goldberg
PACER Center, Inc.

"The opportunity to give children correct information about handicapping conditions"..."Excitement about puppets as a fun and effective medium to teach children"..."The satisfaction that a few fears and misconceptions about people with disabilities have been laid to rest..."

These are a few of the reasons given by volunteers for their participation in COUNT ME IN (CMI), a Minneapolis-based handicap awareness project that has brought puppets portraying children with disabilities into classrooms and before over 40,000 Twin Cities school children since the summer of 1979. Volunteers have always been an important part of the program, originally created by staff members of PACER Center, Inc., the parent coalition in Minnesota.

PACER's parents realized that the entry of handicapped children into the mainstream could be eased if their nonhandicapped classmates understood more about disabilities and, thus, held fewer apprehensions about youngsters with the handicapping conditions. The use of puppets to present the information to children was shortly decided upon as an entertaining and enjoyable medium. PACER's large, hand-and-rod puppets portray children with various handicaps as well as nonhandicapped characters. Their scripted dialogues with each other let the audience know some basic facts about each condition and what it means for the person's life. The central message, however, is that handicapped children are pretty much like everyone else...they like sports and argue with their siblings and have good friends, among many other shared characteristics.

Rather than the CMI staff (two coordinators and one assistant) serving as the sole puppeteers for the school programs, the involvement of volunteers who would be trained in handicap awareness and puppetry techniques was seen as an essential program component for two reasons:

First, according to Polly Edmunds and Rianne Leaf, CMI's staff coordinators, was their interest in increasing the knowledge and awareness levels among adults in general about handicapping conditions — since so many adults had been raised in an era when disabled persons were encouraged to remain out of sight, and polite people were taught not to ask questions about those who did come into public view. Accordingly, the program has recruited volunteers among parents of nonhandicapped children and, in fact, Leaf says, has found more volunteers from those ranks than among parents of disabled youngsters.

A second reason for use of volunteers was to expand the number of children who could be reached by the CMI project. The volunteers have freed the CMI staff from the need to give all puppet shows themselves; hence, staff members have been able to spend more time developing scripts, expanding their training programs, and administering grants that have allowed programs to be developed in other areas of Minnesota.

To date, CMI has trained 493 puppeteers throughout Minnesota and in five other states. Those trained outside the Twin Cities and in other states have then developed their own awareness projects which they administer themselves.

Recruitment

Several routes are followed to recruit volunteers, according to Edmunds, who administers the CMI volunteer program. Articles about upcoming volunteer training sessions are sent to "Volunteers Wanted" columns and community news sections of the Twin Cities metro area daily, weekly, and neighborhood newspapers. The many disability organizations that form the PACER coalition help to publicize the program's needs, and letters are sent to former CMI volunteers, asking that they help with recruitment among their acquaintances. Finally, parents whose children have seen the puppet programs at school will frequently call for more information and, possibly, to become involved themselves.

CMI has no formal, written criteria which potential volunteers must meet in order to participate. Instead, the final selection process occurs gradually as volunteers go through training sessions and begin giving shows. According to Edmunds, usually volunteers who aren't qualified to become puppeteers will themselves sense they aren't doing as well as their team members and will opt for one of the non-puppeteer roles or phase themselves out of the project.

Volunteer Training

All volunteers are required to attend a two-and-a-half-day-long training session where they receive a "training packet" which includes material on puppetry techniques, articles that deal with the feelings and insights of their handicapped authors, and a very important, 106-page *CMI Resource Manual*.

The last, to be read and discussed and kept as a reference, contains facts and information about the various handicapping conditions, describes aids and coping techniques used by disabled persons, gives extensive lists of other reading materials about handicaps, lists questions often asked by children in the puppet show audiences, and suggests "simulation" activities that can be used in classrooms to acquaint children with what having a handicap is like.

After being introduced to techniques, the trainees will then choose the puppet they want to operate. Those metro area volunteers who work on a continuing basis with CMI staff will first go out to do shows accompanied by the staff members. Edmunds spends extra time with beginning volunteers. Having read evaluations completed by teachers whose classes have seen the show and reviewed team members' own critiques, she works with volunteers on any problems that occur.

Later, as the volunteers' expertise develops, they'll be formed into independent teams and go into schools themselves -- though Edmunds will continue to visit periodically and observe how they're doing.

A stipend of $15 per day is paid to each volunteer to cover mileage, food and babysitting expenses. The average time spent per volunteer doing CMI programs is about two days each month.

An Assortment of Backgrounds

Besides parents, volunteers have come from a variety of backgrounds. They include: a professional waiter; a professional actor; former elementary teachers; nurses who've worked with handicapped children in hospitals; a woman who's done summer stock; a TV producer; University of Minnesota students; a woman from South America who helps give programs in schools with bilingual children; Girl Scouts who do shows at their summer camps; and two junior high boys who took the training during a school break and now help with shows during the summer.

Leaf points out that the benefits of training the volunteers has produced results that extend far beyond the CMI project. From interviews with participants at each year's end, the staff has learned that a substantial number have also become involved with many other types of handicap awareness activities working within schools, hospitals, public institutions and churches.

It Works

LeAnne Nelson-Dahl, a CMI staff member who is disabled, speculates that the CMI project has succeeded because "the volunteers believe in the program and what it's trying to accomplish. They're very dedicated to something in which they truly believe."

For more information about the Count Me In Program or the PACER puppets, contact the PACER Center, 4701 Chicago Avenue, Minneapolis, Minnesota 55407.

BIBLOGRAPHY

Books:

Action Through Advocacy: A Manual for Training Volunteers, Edited by Carolyn D. Rude, Research and Training Center in Mental Retardation, Texas Tech University, P.). Box 4510, Lubbock, TX 79409, 1980.

Allen, Kerry Kenn, **Worker Volunteering: A New Resource for the 1980's**, AMACOM, New York, 1980.

Boyte, Harry, **The Backyard Revolution**, Volunteer Readership, P.O. Box 4179, Boulder, CO 80306, 1980.

Brown, Kathleen M., **Keys to Making a Volunteer Program Work: A Guide for Organizations That Use Volunteers**, Arden Publications, 401 Vista Heights Road, Richmond, CA 94805, 1982.

Evaluation of a Volunteer Program, Volunteer Service Bureau/VAC, 122 E. Colonial Drive, Orlando, FL 32801, 1978.

Flanagan, Joan, **The Successful Volunteer Organization: Getting Started and Getting Results in Nonprofit, Charitable, Grassroots and Community Groups**, Contemporary Books, Chicago, IL, 1981.

Guidelines and Standards for Volunteer Programs, Voluntary Action Center, 161 W. Wisconsin Avenue, Milwaukee, WI 53203, 1979.

Vineyard, Sue, C.V.M., **Finding Your Way through the Maze of Volunteer Management**, Reporter/Progress Newspapers, 922 Warren Avenue, Downers Grove, IL 60515, 1981.

Volunteer Readership, (Annual Catalog), VOLUNTEER: The National Center for Citizen Involvement, P.O. Box 1807, Boulder, CO 80306.

Wilson, Marlene, **The Effective Management of Volunteer Programs**, Volunteer Management Associates, 279 S. Cedar Brook Road, Boulder, CO 83302, 1979.

Wilson, Marlene, **Survival Skills for Managers**, Volunteer Management Association, Boulder, CO, 1981.

Periodicals:

Journal of Voluntary Action Research, Association of Voluntary Action Scholars, S-211 Henderson Human Development Building, Pennsylvania State University, University Park, PA 16802, (Published quarterly).

Notebook, Association of Volunteer Bureaus, 801 N. Fairfax Street, Alexandria, VA 22314, (Published monthly).

Voluntary Action Leadership, National Center for Citizen Involvement, P.O. Box 4179, Boulder, CO 80306, (Published quarterly).

Organizations:

VOLUNTEER: The National Center for Citizen Involvement
P.O. Box 4179
Boulder, CO 80306
(303) 447-0492

1111 North 19th Street, Suite 500
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(Services include extensive library on voluntarism and distribution services for works in the field, consultation, training, and evaluation.)

Local resource organizations that can offer invaluable resources are local Voluntary Action Centers (or Voluntary Action Bureaus) and Directors of Volunteers in Agencies (DOVIA). Your local Chamber of Commerce, the phone book, or your State Office of Volunteerism may help you locate them.

COALITION QUARTERLY

A Publication Offering Specialized Management Information for Organizations Serving Handicapped People

Volume III *Number 3*

RECENT DEVELOPMENTS

EDUCATION OF THE HANDICAPPED ACT AMENDMENTS OF 1983, SECTION 631.. 1

JAMAS SERAN VENCIDOS 3

This is the final issue of **Coalition Quarterly** to be published under this contract with the U.S. Department of Education, Office of Special Education and Rehabilitation Services. Since the first issue was published in 1980, our purpose has been to offer the specialized management assistance needed by parents to set up and operate centers that would offer training and information services to other parents of children with disabilities. Although parents are motivated to develop such programs to meet pressing needs, often the activities involved in administering such a center are so demanding as to eclipse the original motivation. The intention of **Coalition Quarterly** has been to supply management information that would promote the stability and accountability of the programs, and at the same time allow the energy behind the commitment to flourish.

Since that first issue was published, some important changes have taken place. The parent movement has gained momentum; parents are recognized as the new professionals in special education and rehabilitation. Originally, official acknowledgement came from framers of P.L. 94-142 who included parent participation in every aspect of developing and implementing each child's individualized educational program. Now, through the Education of the Handicapped Act Amendments of 1983, P.L. 98-199, signed into law on December 2, 1983, the critical role that parents play in the education of their handicapped children, and as teachers and supporters of each other, has received even more official recognition. The Amendments of 1983 underscore the original intent of the law by requiring that a specified percentage of the annual education appropriations be set aside to support parent-to-parent training and information projects throughout the nation.

This issue of **Coalition Quarterly** begins with a brief introduction to the new amendments, and then quotes the entire section that pertains to parent organizations. The second article has been prepared by Richard M. Lash, former project director of the Direction Service operated by Community Service Society of New York City, and now executive director of *Sinergia, Inc.* Mr. Lash's article has been chosen to close this series of **Coalition Quarterly** for two reasons. First, the story described here illustrates many of the questions received by this project over the years: How to organize parents in the first place, and, then, how to keep them together in a viable and energetic group. The parents described by Mr. Lash provide a sterling example of the commitment, innovativeness, hard work and joy that

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combine to form the driving force of such efforts when parents are bound by a common goal. Second, the parent leadership that Mr. Lash described embodies much of what the Congress of the United States chose to support with the new legislation.

Celebrations are in order on both counts: The law will make possible stronger and better organized parent involvement. And, as of June 1984, the New York *Padres'* organization has just received its first contract with the N.Y. City Youth Bureau to operate their own parent-run Direction Service.

EDUCATION OF THE HANDICAPPED ACT AMENDMENTS OF 1983: Introduction and Text of Section 631 (c), (1)-(7)

This past year has been a landmark year legislatively: Both the Education of the Handicapped Act and the Rehabilitation Act were due for reauthorization. Congress deliberately timed these two laws for simultaneous renewal in order to emphasize the intention that there is to be a **continuum** of services, rather than two mutually exclusive systems, devoted to serving persons with disabilities. John Doyle, Majority Staff Director of the Senate Sub-committee on the Handicapped, summed up this year's legislative work as follows: " . . . looking now at the special education and rehabilitation provisions that resulted from last year's legislative activities—where programs were continued, where programs were enhanced, and funding levels were increased—if you look at all these provisions together, I think it is fair to say that you could group them all under the category of being client-centered provisions, that are much needed."

Space limitations prevent a lengthy summary of these laws. The editors recommend that readers obtain copies of each of these laws and the accompanying reports. The Special Education Amendments are P.L. 98-199, and are explained in Senate Report No. 98-191. The Rehabilitation Act Amendments, P.L. 98-221, are discussed in the House of Representatives Report No. 98-595. The March/April issue of **Programs for the Handicapped** contains a one-page point-by-point summary of the Rehabilitation Amendments. Copies are available free from: Programs for the Handicapped, CLEARING HOUSE ON THE HANDICAPPED, Office of Information and Resources for the Handicapped, Room 3132 Switzer Building, Washington, D.C. 20202. Telephone: (202) 732-1248 or 732-1245.

Section 631 (c)(1) through (7)

There are specific components of the Amendments of the Handicapped Act of 1983, which embody many of the philosophical, structural, and organizational principles discussed throughout the series of **Coalition Quarterly**. Following is the new section of the law that establishes a federal program for parent training and information:

(c) (1) The Secretary is authorized to make grants through a separate competition to private nonprofit organizations for the purpose of providing training and information to parents of handicapped children and volunteers who work with parents to enable such individuals to participate more effectively with professionals in meeting the educational needs of handicapped children. Such grants shall be designed to meet the unique training and information needs of parents of handicapped children, including those who are members of groups that have been traditionally underrepresented, living in the area to be served by the grant.

(2) In order to receive a grant under this subsection a private nonprofit organization shall—

(A) be governed by a board of directors on which a majority of the members are parents of handicapped children and which includes members who are professionals in the field of special education and related services who serve handicapped children and youth; or if the nonprofit private organization does not have such a board, such organization shall have a membership which represents the interests of individuals with handicapping conditions, and shall establish a special governing committee on which a majority of the members are parents of handicapped children and which includes members who are

professionals in the fields of special education and related services, to operate the training and information program under this subsection;

(B) serve the parents of children with the full range of handicapping conditions under such grant program; and

(C) demonstrate the capacity and expertise to conduct effectively the training and information activities authorized under this subsection.

(3) The board of directors or special governing committee of a private nonprofit organization receiving a grant under this subsection shall meet at least once in each calendar quarter to review such parent training and information activities, and each such committee shall advise the governing board directly of its views and recommendations. Whenever a private non-profit organization requests the renewal of a grant under this subsection, the board of directors or the special governing committee shall submit to the Secretary a written review of the parent training and information program conducted by that private nonprofit organization during the preceding fiscal year.

(4) The Secretary shall ensure that grants under this subsection will—

(A) be distributed geographically to the greatest extent possible throughout all the States; and

(B) be targeted to parents of handicapped children in both urban and rural areas, or on a State, or regional basis.

(5) Parent training and information programs assisted under this subsection shall assist parents to—

(A) better understand the nature and needs of the handicapping conditions of their child;

(B) provide followup support for their handicapped child's educational programs;

(C) communicate more effectively with special and regular educators, administrators, related services personnel, and other relevant professionals;

(D) participate in educational decisionmaking processes including the development of their handicapped child's individualized educational program;

(E) obtain information about the programs, services, and resources available to their handicapped child, and the degree to which the programs, services, and resources are appropriate; and

(F) understand the provisions for the education of handicapped children as specified under part B of this Act.

(6) Each private nonprofit organization operating a program receiving assistance under this subsection shall consult with appropriate agencies which serve or assist handicapped children and youth and are located in the jurisdictions served by the program.

(7) The Secretary shall provide technical assistance by grant or contract, for establishing, developing, and coordinating parent training and information programs.

JAMAS SERAN VENCIDOS

By Richard M. Lash, Executive Director of *Sinergia, Inc.* 150 W. 105 St., New York, N.Y. 10025

"*Los Padres—Unidos—jamas seran vencidos!*" The parents united, will never be defeated! Witnessing their spirit, dignity, and unity, it seems that they will not be defeated—but who are these *Padres*?

Los Padres Unidos are parents and families of handicapped children and youth. They share the streets, tenements, housing projects, bodegas and botanicas in the Manhattan Valley neighborhood of New York City.

The Padres are united because as vulnerable individuals they know, all too well, that they can be defeated. Eighty percent of the families are single parent, female headed households with one or more handicapped children. Only a few speak English, many do not have telephones, and many require an escort/translator to assist them in using the subway system to keep appointments at hospitals and special education schools.

They are united because they found the help they needed in Direction Service, a federally funded program operated by the Community Service Society (CSS) to assist families in securing the special education and related services that their children require.

Crisis

Since federal funding would end completely in 1982, new funds or new means had to be found to continue the Direction Service activities. The resolve of the parents was immediately apparent. They were not going to accept the dissolution of what had now become **their** program. After brief considerations they rejected a suggestion for a protest demonstration. They favored a positive action! They, who had little or no experience in organizing, decided to organize to help themselves and their children.

Response from the Fathers and Mothers

A father volunteered that he had fashioned a cart from which he could sell orange juice on the corner, and the profit would go toward the maintenance of the Direction Service. A mother recalled her experience in the needle trades and offered to make items to sell, while another stated that her former employment had been in food services and she could prepare food to sell. Considering the group's common skills and the immediate market, *Los Padres* began their first common effort: They would prepare lunch to sell to the faculty of Public School 145, on the first Friday of the semester. The announcement of the luncheon was well received by the teachers and staff of PS 145 and some community persons said they would attend also. In the two hours that *Los Padres* served *comidas criollas* (native foods) they grossed $170.00. They had worked together, and judged themselves successful in their first venture. Moreover, people began to know of their organization and their resolve. During the lunch, they had also received an offer to cater an open house at the opening of a local office of a community agency.

The catering arrangement was successful and the *Padres'* effort was noted by community leaders and elected representatives, most notably their local representative on the City Council. As a result of the parents' efforts, CSS promised emergency assistance. That assistance provided supplemental funds and helped support what would become a joint task force to plan for Direction Service and *Los Padres Unidos*, who had signified their intent to institutionalize the project by becoming a formal, community-based organization.

During October 1981, *Los Padres* conducted a raffle and a cake sale, again experiencing a modest success financially and remarkable success in working together. In early November, they thought about Thanksgiving and how many of their members, as well as their neighbors, do not have even adequate food, let alone, a holiday family dinner. They solicited donations of food from each other, the PS 145 faculty, Direction Service staff and CSS personnel. All responded and the local merchants began to donate foodstuffs. A few Columbia University fraternities joined the effort. Cash donations enabled the committee to include one or two Thanksgiving chickens in the baskets which totaled about forty, exceeding their original goal of twelve baskets for needy families.

By Christmas of 1981, *Los Padres* were busy planning a toy distribution and family dinner for the holiday.

Appeal to N.Y. City and State Officials

With the help of a local community organizer, *Los Padres* met with the local representative from the New York City Council and then approached the N.Y. City Youth Board for funding to support Direction Service.

While the application to the Youth Board was being requested, *Los Padres* wrote to the Assistant

Commissioner of the N.Y. State Department of Education requesting that any available resources for handicapped children be utilized in a way that would reflect the planning and needs of minority parents. The Commissioner came to New York to meet with *Los Padres*, giving them the opportunity to present their needs face to face. The *Padres* gained approximately half of the financial support required for Direction Service at that meeting, and in return promised to translate existing Spanish parent material into colloquial langage for families, as well as to secure additional funding from other sources. While reporting their success at the next Task Force meeting, they learned that CSS had allocated sufficient funds for a N.Y. City Youth Board matching grant, which would, with the State Education Department contract, continue the Direction Service throughout the 82-83 fiscal year without federal funding.

The combined support of the State Education Department, the City Youth Board, and the Community Service Society not only allowed the Direction Service to continue its individual case work for the children and families, but also to create a formal component of self-help groups for youth and families. Individual assistance was still available, but the families could now attend group sessions to plan and learn from a curriculum which would offer information, material and experiences to foster their attempt to manage independently. Further, the curriculum offering was structured so that they could function in the groups collectively, individually, and as members of a developing corporation.

Los Padres Unidos is working with the sponsoring agency, CSS, to eventually replace CSS as the incorporated, non-profit community-based organization which will operate Direction Service. The activity brought those parents with leadership ability to the fore, and has allowed the membership to select and approve its leaders while forming a membership structure.

Self Discovery

As *Los Padres* planned for their children, and assessed needs and resources, they gradually went through a process which refocused their view. When they were given the opportunity, and a structure within which they would do their own planning, they found it difficult to isolate their focus to the needs of their handicapped children for special education and related services. It seems that they began to re-evaluate their own lives as parents, and the needs of their family as a whole. Although their assessments and discussions revealed needs ranging from legal services to adequate, affordable housing, the two top priorities, invariably, were and are, education and job preparation. As they looked at the needs of their children, they saw their own needs, hopes and ambitions. The direction, which they gave to Direction, was that we cannot improve the opportunities for our handicapped children without attention to the total family needs. Conversely, their effort to enhance the well-being of the family unit was viewed as improving the opportunities available to their handicapped children. It seemed so easy for professionals to isolate their handicapped children for a specific service, e.g., education. And it seemed so difficult, or perhaps unnatural, to *Los Padres* to select one service from all of their interrelated needs.

They sought an alternate form of income production, one which would reconcile their need for day care, their inability to travel to distant parts of the city, their limited language ability and their marketable skills. Ultimately, they joined with several other similarly interested groups to form a *"cooperativa"* (cooperative), which they would operate and control as workers. *Los Padres* brought to the new cooperative, their experience in the needle trades and garment industry.

The total concept of *Los Padres* was a cooperative that could accommodate both parents and young people with disabilities. It would eventually be associated with a work development center in a comprehensive educational, training and employment program. Meanwhile, they knew that they needed expert guidance, and again appealed to CSS for technical assistance. The sponsoring agency responded through its Center for Economic Development and assigned personnel to assist *Los Padres Unidos*.

Steady Growth and A Bright Future

While *Los Padres* have demonstrated both interest and industry in planning for themselves, they have also found time to help others, to reach out to the Hispanic community-at-large, and to enjoy the City's cultural and recreational opportunities as families.

The second annual Thanksgiving Food Distribution exceeded all expectations, filling over 150 baskets and included a family dinner prepared by *Los Padres*. The activity received major media attention in New York City.

When *Los Padres* joined the National Congress for Puerto Rican Rights, they organized and conducted the first workshop on the needs of Hispanic handicapped children for the National Congress.

Los Padres have also found time for family and community activities. The first family outing to Jones Beach was held last summer with help from the N.Y. City Youth Board and Community Board #7. Another activity took the families to Rockefeller Center to view the Christmas tree which most had only seen on TV, the ice skating rink and Christmas store windows. A children's choir was formed and caroled in the neighborhood, at a Manhattan Cable TV children's party and at CSS. With the help of Con Edison, *Los Padres* attended an Hispanic opera at Lincoln Center. Ringling Brothers-Barnum and Bailey arranged for a real circus clown to visit and perform for the children at the Direction Service site a week before they provided tickets for 300 children and parents to attend a matinee during the spring school recess.

To keep its membership informed and interested, as well as to communicate with a network of people important to their mission, *Los Padres Unidos* established a newsletter which they appropriately named *"Los Padres Unidos."* Parents and youth contribute stories, drawings and announcements.

On July 5, 1983, the *Padres* were incorporated under the name *Sinergia, Inc.*, which means synergy. The majority of the governing board members are minority parents of handicapped children and youth. They serve all categorical handicaps and developmental disabilities.

"Los Padres—Unidos—jamas seran vencidos!" The parents, united, will never be defeated! To date, they have taken important steps toward their goal of enhancing the well-being of minority families with handicapped children. They have suffered setback and disappointments, but have shown perseverance and determination. They have gained individual and group confidence. They are unknowingly beginning to emerge as a social conscience for the establishment's decision makers. These *Padres*, who as individuals have been so vulnerable, have not, as a group united, ever been defeated!

Coalition Quarterly

Vol. 4, No. 1 Fall 1984

A Journal of the NATIONAL NETWORK OF PARENT CENTERS

Client-Centered Provisions of Special Eduction and Rehabilitation Act Amendments

John A. Doyle, *Majority Staff Director of the U.S. Senate Subcommittee on the Handicapped, gave the following talk at a recent conference on "Transition," held in Washington, D.C. The speech is included here because it summarizes a number of issues that are of primary interest to coalitions working for people with disabilities; of particular interest is Mr. Doyle's discussion of the inter-related roles of special education and vocational rehabilitation in providing a continuum of services. Mr. Doyle's speech:*

Before beginning my remarks, I express to you Senator Weicker's greetings and best wishes for a successful and productive session here in Washington. As chairman of the authorizing and appropriations subcommittees concerned with individuals with disabilities, the Senator has, as you know, become a principal spokesman for those who cannot, often, speak for themselves. The work I will describe to you today is indeed his work in which I am proud to have played a supporting role.

This issue of Coalition Quarterly reviews recent legislative initiatives in the field of special education and vocational rehabilitation. The first article presents significant revisions in the special education and rehabilitation laws. The second article reviews the historical development of the "least restrictive alternative" concept and discusses the emerging roles of families and communities in making this concept a reality in the lives of children and adults with disabilities.

First, A Legislative Primer

As you know, there are two kinds of laws enacted by the Congress. One is an authorizing law which is merely a statute that says a certain thing shall be done. Being a smoker, I'm fond of using the ashtray metaphor. Let's say we decided that everybody in America was going to get an ashtray. Undoubtedly, it would be of a certain size, shape, weight, and be inscribed in a certain way, this year maybe with the International Olympic symbol. Let's say that we put all these requirements together into a bill, which then passes the House and the Senate, the President signs it, and it becomes law.

It is not an accident that both of these programs appeared on the calendar for reauthorization during the same year.

Does that law get any ashtrays out? No. That is called an authorizing law; it merely establishes a requirement that something is going to be done. The next part of the process occurs when the Appropriations Committees determine that, in order to make this requirement work, we need to fund it at x millions of dollars. Once that is done, and the Good Lord and the regulation writers willing—not necessarily in that order—perhaps the ashtrays will get out to all Americans.

Then, every so many years, authorizing laws come up for renewal. Congress must again take a look at them, must again say whether the programs should be continued, whether the ashtrays should continue to go out. In the course of this review—a process called reauthorization—Congress may decide that some changes are needed. Maybe, instead of displaying the International Olympic symbol, the ashtrays ought to contain some other message.

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That process is exactly what happened last year, when the Congress undertook reauthorization of the Vocational Rehabilitation Act and the discretionary programs in the Education of the Handicapped Act. It is not an accident that both of these programs appeared on the calendar for reauthorization during the same year. Back in 1981, the Subcommittee on the Handicapped took action to make both programs expire at the same time in order to give Congressional emphasis to the fact that there are not two mutually exclusive systems here. Rather, what there is is a person with a disability and a continuum of services to try to serve that person.

Hearings were held; some of you took advantage of the opportunity to let the Congress know what you thought of the Vocational Rehabilitation and the special education acts. We proceeded from the hearings to markups in committees, and then to passage by both the House and Senate. In December 1983, the President signed the new Education of the Handicapped Act Amendments, and on February 22, 1984, the President signed the Vocational Rehabilitation Amendments.

As Congress began work on these two laws (and I think I can speak for my House conterparts as well here) we adopted Sam Irvin's advice: 'If it ain't broke, don't fix it!'

Summary of Major Provisions

Although I, and others, will summarize for you the major provisions in these two laws, I urge you to read each law. Why? Because the law is what counts. Regulations, requests for proposals, informal comments by Congressional staff or others do not count. THE LAW COUNTS. YOU OUGHT TO READ IT. It is important that you know the structure within which you will operate for the next three years, when the next reauthorization process takes place.

This journal is prepared under Grant No. 029PH40047, awarded by the office of Special Education, U.S. Department of Education. Grantees undertaking such projects under government sponsorship are encouraged to express freely their judgment in professional and technical matters. Points of view or opinions, therefore, do not necessarily represent the Education Department's position or policy.

The National Network of Parent Centers is coordinated by the Federation for Children with Special Needs 312 Stuart Street, Boston Massachusetts 02116

Martha H. Ziegler, Executive Director
Janet R. Vohs, Editor

As Congress began work on these two laws (and I think I can speak for my House counterparts as well here) we adopted Sam Irvin's advice: "If it ain't broke, don't fix it." We took a look at the various sections of the laws, with a view towards continuing and enhancing what was good, and to see if we could even make it a little better.

Vocational Rehabilitation Program Changes

Discretionary Programs

As you know, 90 percent of the vocational rehabilitation dollars go to the states for basic vocational rehabilitation services, and the other 10 percent go for a wide variety of federal discretionary programs. Discretionary activities are funded to supplement the main law. For example, the law says that we will have vocational rehabilitation in each of the states. In order to do that, we need trained personnel. Therefore, there is a part of the law that establishes a training program. This money, funded at just over 20 million dollars, goes to the States and to the regions to train counselors and other kinds of persons to work in the vocational rehabilitation process.

There is also a National Institute of Handicapped Research (NIHR) for both basic and applied research activities funded at about 36 million dollars. Personnel training, the NIHR, the program for migrants and so forth, are all discretionary activities, funded by that remaining 10 percent of federal funds. The federal funds that go to the states for direct services (90 percent of the total), must be matched with state dollars, resulting in services being funded 80 percent with federal funds and 20 percent with state funds.

The National Council on the Handicapped, up to very recently, had been very little more than a public relations vehicle to carry the water for whatever administration was in power.

As most of you know, the formula is quite different in special education. For direct services to disabled children, the federal government picks up something less than 10 percent of the cost, and state and local governments must pay the remaining 90 percent of the cost.

Most of the rehabilitation programs "were not broke," so we did not try to "fix" them. We merely did some fine tuning. For two programs, Projects with Industry and the Independent Living Centers, we decided to add an evaluation requirement that will lead to a set of standards for carefully adding these two programs to the permanent rehabilitation structure.

A Major Program Shift

The National Council on the Handicapped, up to very recently, had been very little more than a public relations

vehicle to carry the water for whatever administration was in power. While the Council was statutorily authorized to make recommendations to the Secretary, the President, and the Congress on disability policy, it was in fact subordinated to whatever political winds were blowing at the time. That certainly was not the intent of the original drafters of the law, and it was not sufficient for the present Congress. As of February 22, 1984, the National Council on the Handicapped became an independent federal agency, not within the Department of Education. The Council now has broad statutory authority to survey widely and deeply our disability laws and programs, determine how they might be improved, and to make recommendations directly to the Congress without any screening. Also, the National Council on the Handicapped now has statutory authority to approve or deny the regulations for the Projects with Industry and the Independent Living Centers before they are issued.

The last change I will mention in the Rehabilitation Act is that the Client Assistance Program (CAP) has been made a mandatory part of the Act. Each state must have a CAP, a program which must be available to assist clients, parents or guardians. It must assist them both administratively and legally. In setting up the program, each governor must, by statute, seek and heed the advice of interested parties, including a broad spectrum of disabled people, their organizations, and advocates. This Client Assistance Program, in my view, is long overdue in each of the states to assure that client rights become a coequal part of the services being provided.

Special Education Program Changes

With special education, you are much more familiar. You know that under the Education of the Handicapped Act Amendments of 1983, activities may begin at birth. You know that there is now a six million dollar program to fund demonstration models on transitional services; you also know that, after having spent literally hundreds of millions of dollars teaching administrators, school teacher and others how to strategize to cope with parents, we are now going to spend at least ten percent of the training dollars training parents how to know and insist on their rights. This, too, is overdue.

Summary

Wordsworth talked about "emotion recollected in tranquility," as a definition of poetry. It is dangerous to go back and put wholesale labels or descriptions on work so recently completed, especially legislative work. Nevertheless, looking now at the special education and rehabilitation provisions that resulted from last year's legislative activities, where programs were continued, enhanced, and funding levels increased, I think it is fair to say that the major new thrusts involved client-centered provisions.

Requiring a Client Assistance Program in each state, making the National Council on the Handicapped an independent agency, setting aside a definite amount of the training money each year to make sure that parents get a shake in the process, all of these could easily be grouped under the category of client-center provisions that are much needed.

NOTE: To obtain a copy of the Rehabilitation Act described above, PL 98-221, with a full explanation of its provisions, ask for Report 98-595. For the Education of the Handicapped Act Amendments, PL 98-199, ask for Report 98-191. These documents will be sent to you free of charge if you write to:

Senate Subcommittee on the Handicapped
113 Hart Senate Office Building
Washington, D.C. 20510

Community Living Alternatives

Professor Gunnar Dybwad *presented the following speech on Community Living Alternatives at a recent national conference for leaders of parent coalitions. The overwhelmingly positive response of the parent leaders to Professor Dybwad's speech prompted our inclusion of it here; first, to serve as a further articulation of the rights of people with disabilities, and second, to give some background to the concept of community living.*

Professor Dybwad brings to the disability-rights movement fifty years of involvement in human services, beginning with his work with juvenile delinquents in prisons where the close relationship between delinquency and disability was inescapable. His view of the rights of children with special needs is informed by the perspective he gained from the larger world of the child-welfare system.

Over the years, his broad involvement with the rights of people with disabilities has touched upon almost every domain of life—from education, to life style, to leisure, to architecture and design—and has taken him to many countries. He has recently served as President of the International League of Societies for Persons with Mental Handicaps, the international counterpart of

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ARC-US.

Professor Dybwad teaches at Syracuse University and is professor emeritus at Brandeis University.

Historical Perspective

My theme today is community living alternatives. This term has been used in recent years to emphasize the imperative that alternative placements should, and can, be made available for persons in institutions. If they are children, the placement of preference is, of course, their own home, or, if that is not feasible, some other family-like arrangement, such as a foster home or small-group home. Some of you may wonder why this is such a revelation. To explain this strange situation, we must question why, for many years, we essentially ignored and devalued the family as a focal point of helping children with severe handicaps.

They were tired and resentful of society's discrimination against their children, and the discrimination which hurt them most was the discrimination in education.

About thirty years ago, parents of children with severe handicaps gathered together in protest in many countries around the world. They were tired and resentful of society's discrimination against their children, and the discrimination which hurt them most was the discrimination in education. They had learned to cope with the fact that, during their child's early years, they could not get adequate medical help, that no attention was given to their children's developmental needs, and that there was no relief for them in the 24-hour daily care of their children. But, when that child, upon reaching school age, was barred from school, school being the most basic general experience of any child in this and other countries, this situation became intolerable.

I think the timing of this parental rebellion across the world had something to do with the end of World War II, for it was then that, for the first time, rehabilitation became a reality on a large scale. Until that time, rehabilitation had been reserved for railroad workers, miners, and so on; but rehabilitation as a broad program, or a movement, only occurred as a result of World War II. In contrast to all the negative things that happened during World War II, this was one very positive outcome. And this is what apparently triggered parents in many countries—France, Norway, Sweden, Australia, the United States—at just about the same time, to rebel on behalf of their children.

There are some old-timers in this room who remember how these parents not only built or rebuilt the schools, painted the schools, provided the desks and materials, but also taught in the schools. Of course, they knew that was not the best way to go about it, and soon, educators were brought in to help. Work training, sheltered workshops, opportunity workshops, whatever you may call them, became the next order of business. Organized recreation entered the picture when we begged the YMCA to give a little space and some special hours when the swimming pool was made available; because, in those days, it was unthinkable to have handicapped children swim with other people.

Because of the technical nature of the schooling, the people outside the home began to be regarded as the experts.

So, there was movement and progress, but this initial impetus was all outside the home. All the legislation that was written, all the appropriations that were made, were for services outside the home. Because of the technical nature of the schooling, the people outside the home began to be regarded as the experts. This development created a very strange situation and it is really not an exaggeration to say that in the shuffle—and it was a shuffle just to keep all these things going—the family was lost and forgotten.

I hope some of you remember what the Queen said when Alice asked, 'Where shall I begin?' She said, 'Begin at the beginning.'

A prime factor in the support which must be developed is early intervention.

Rediscovering the Family

I wanted to bring this picture of the early days to you so that you might understand why some of us say now with great satisfaction that we are rediscovering the family. I am apt to say when I talk to audiences, that we have a lot to learn from Lewis Carrol's *Alice in Wonderland.* I hope some of you remember what the Queen said when Alice asked, "Where shall I begin?" She said, "Begin at the beginning." And that is the exciting new situation now. It is what has so basically changed the field.

It is hard for some of you newcomers to imagine what a shift it is, what a fundamental change, to go back to the family and recognize that the key is there. Our challenge has been stated simply and directly by Ed Skarnules—"support, not supplant, the natural home."

In the past, the tendency was to supplant. Social

workers felt that parents were too anxiety-ridden to take care of their severely handicapped children. Physicians wanted to "protect" the parents, so condemned the children to institutions. Everybody, you see, had this feeling that the family was incapable. Brothers and sisters were considered only as exploited people, nobody thought of the contributions they could make and the resulting protection and support of them. So "support, not supplant" the natural home is the motto that really is carrying us forth and will bring us closer to my theme today.

Beginning At Birth

Many of the problems faced by families of children with severe handicaps are due to unnecessary deprivation, neglect, and rejection beginning practically at birth. I am still being shocked today by incredible stories told by reliable parents of what physicians tell them, and what the community did **not** have available for their handicapped infant.

A prime factor in the support which must be developed is early intervention. The beginning, of course, will bring us to the delivery room. In some countries, and increasingly in ours, it will bring us to the midwife, and to the moment when the mother is first made aware that she has given birth to a child with a severe handicap.

Any discussion of future developments in the field of childhood disabilities needs to proceed from a recognition of the inherent strength of the family to deal effectively with the demands of raising a child with a disability, provided the community is ready and willing to lend its support.

There is one question I would like to ask you, to make clear how little we know and how much we have yet to learn and to organize on the basis of our learning. This is a very simple question, which I have asked in Bangalore, India, in Melbourne, Australia, in Warsaw, Poland, in many cities in this country, indeed, anywhere in the world: If in your community, a child is born with a serious, immediately discernible impairment, what happens? Who tells what to whom, and how is this initial message translated into appropriate action? Ask yourself this question: What would happen, if tonight in the hospital in your neighborhood, in the hospital nearest you, a child is born with, shall we say, spina bifida? Who will see to it that there is appropriate action to bring this family needed supportive services without any damaging delay?

Now, let me summarize this part of my remarks. Any discussion of future development in the field of childhood disabilities needs to proceed from a recognition of the inherent strength of the family to deal effectively with the demands of raising a child with a disability, provided the community is ready and willing to lend its support.

Previous Assumptions

This recognition deviates distinctly from assumptions and beliefs commonly held until the recent past. In many cases, today your physicians still hold these views. As a matter of fact, most people with professional training, or those who have simply read textbooks, still believe this. (If you pay $56 for a textbook today, you had better believe what is in it.) They really believe that those wholesale denials of the ability of families and the capabilities of people with disabilities were based on scientific evidence. In special education, as you know, we used research evidence as the basis for denials of educability which we know today were absolutely wrong. Not only do we know they are wrong, but we have proven that they are wrong. So, this is one point you must keep in mind to see the magnitude of the change that is taking place.

Today there is ample, uncontradicted evidence in the literature of many countries that it was, as a consequence of inappropriate counseling from professional sources and the community's unwillingness to render assistance, that parents concluded they were unable to cope with their severly handicapped child. As a result, a massive political structure of social services, not limited to institutions, has been substitued for the care of the family. It is only natural that, from within this massive service system based on public appropriations, we encounter resistance to change.

When A Family Can't Cope: Parent and Child Rights

The emphasis on the family and on the roles and rights of parents does not exclude an equal emphasis on the rights of the child with a disability. While we emphasize that the family should be supported and allowed access to the facilities and services needed to deal effectively with a child in their own home, we must realize that there are families that simply cannot cope with a severely handicapped child.

Unfortunately, if there is a disability, the child is often transported to a closed institution, which is a polite term for jail.

In other situations, where there is no disability, the answer is very clear: the child goes to another family. Unfortunately, if there is a disability, the child is often transported to a closed institution, which is a polite term for jail. This would never occur in the child welfare system, but ours is a peculiar situation.

The fact that the child has rights needs to be recognized. This is something which, in many cases, parents cannot

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understand. I am very much concerned about cases of youngsters with disabilities whose parents simply state, "If we don't want our child, it's our business." Of course, it is most decidedly not only their business; it is the child's business.

Parents' basic rights are not inherent in parenthood, but in personhood. Their rights as individuals, in individual citizenship, are similar to those of the child. They have rights; the child has rights. These rights have been articulated very clearly through the United Nations' emphasis on human dignity which resulted in the United Nations Declaration of Human Rights. While the parents who cannot cope have the right to our support, support by relieving them of caring for the child, the child has the right to live in a family.

Parents' basic rights are not inherent in parenthood, but in personhood. Their rights as individuals, in individual citizenship, are similar to those of the child.

In case of conflict, the scales of justice have to be put into balance. If, on the one hand, parents are embarrassed to have their child live in the community, and, on the other hand, the child has the right to life and welfare, then obviously the parental embarrassment will not outweigh the child's right to live in the community.

Least Restrictive Alternative

Since many of you have been primarily oriented to special education programs, I think I can strengthen the argument for community living alternatives by reference to a very important document originating with the Council for Exceptional Children. This document was passed by the open convention of the Council for Exceptional Children in April, 1971. The date is important because it predates two important right-to-education federal court cases, *PARC v. State of Pensylvania* and *Mills v. Board of Education of the District of Columbia.*

The document, "Basic Commitments and Responsibilities to Exceptional Children," first asserts the principle that all children have educational rights, and then it says something very important: "Since the passage of the first public-school laws in the mid-nineenth century, the principle has received general endorsement and qualified execution. While lip service has been paid to the intent of the principle, various interpretations of the terms 'education' and 'all children' have deprived many children of their rights."[1] I want to emphasize that, with this document, a professional organization did more than make promises for the future; it had the courage to acknowledge past shortcomings and to call for needed change. The document sets forth the needs of children with special learning problems, with a particular emphasis on their needs in the family.

One point which I would like to underline here deals with the placement of children in special school programs. Many of you have heard of the concept of least restrictive alternative. This concept was developed by a special educator from the midwest, Maynard Reynolds, and published in 1962 in *Exceptional Children.* In this article, "A Framework for Considering Some Issues in Special Education," Dr. Reynolds outlines, in terms of special education, the proposition that a child should be restricted from general school only to the extent and degree that is actually needed. I emphasize that this concept has it origin in special education.

Today we say "mainstreaming," which is continually wrongly interpreted as simply placing children in regular classes. What it really means is a direction: You bring the children closer to the mainstream; you do not dump them in the middle of the river. Mainstreaming follows a developmental process. It is often deliberately misinterpreted, just as people have misinterpreted the process of deinstitutionalization for adults.

Problem Areas

From the information presented so far, we can discern two problem areas. One is concerned with bringing to the families with young, severely disabled children the kind of financial and other support they need to care for their children. Obviously, maternal and child health services are central to discussions of services for these families.

While the parents who cannot cope have the right to our support, support by relieving them of caring for the child, the child has the right to live in a family.

The second problem area, and the one which relates specifically to our theme, is that of children, young people, and adults who presently are confined in state institutions, for whom alternative residential accommodations can and must be made available. (My discussion does not include mental hospitals and other facilities for the treatment of mental illness and acute mental disturbances, not because these problems are not pressing, but only because I am not competent to discuss them in depth.)

I come from the field of child welfare. Children's institutions were virtually eliminated four decades ago. Large congregate schools for the blind and deaf have disappeared in many states. Deinstitutionalization is not new; it has been with us. But, we are still looking to find ways to deal with this problem, and the problem is tremendous. The

[1]Reynolds, Maynard, CEC Policies Commission Chairman, "Basic Commitments and Responsibilities to Exceptional Children," a Position paper adopted by the Council for Exceptional Children at its Miami Convention in April, 1971. Reprinted in *Exceptional Children,* 38, 2 (October 1971)

Secretary of Health and Human Services appeared in my state of Massachusetts to insist that the state spend 40 million dollars to upgrade a state institution which a federal judge called a pigpen three years ago. Even after having spent 40 million dollars of tax money, the result can still only be a redecorated pigpen.

One Solution

On the positive side, we now have in the making a possible solution: an amendment to the Social Security Act which, over a period of time, would assist the individual states to shift the federal share of medicaid funds for long-term institutional arrangements to community-based, integrated, family-scale environments. What has happened nationwide over many years is that federal support was contingent upon certifying that people with disabilities needed medical care. So, program administrators certified that people who were by no means sick and did not need medical care, needed it. Now there is a possibility that this requirement will be turned around so that federal resources can be used to reinforce community living, and not to maintain institutions. This funding shift would also affect those persons with developmental disabilities in terms of a new definition, one which would not be limited to children with mental retardation, cerebral palsy, epilepsy, and neurological disorders, but to anybody with a developmental disability including physical disabilities, with the exception of mental illness.

I have every sympathy with the parents who were persuaded and often pressured to place their children in institutions.

But I do want to point out that we still have some problems that need to be attacked. I want to make one point quickly, unless I be misunderstood: I have every sympathy with the parents who were persuaded and often pressured to place their children in institutions. Their children have been in these institutions for twenty and thirty years. Such a parent may simply not be able today to say, "Oh, you want to place my child in the community; fine, I understand." I understand and defend the parent. The people I am attacking are my professional colleagues who have done the deed, not the parent.

May I share with you a story. It is a lovely story about a mother whom I know well, who had a child with Down's Syndrome in New Jersey, and had been pressured to place the child in an institution. She resisted, but the pressure continued and she was made to feel that she was quite irresponsible to her other children, as well as to the child with the disability. She finally called what in those days was the Department of Institutions and Agencies in Trenton, and said to the switchboard operator, "I want to talk with somebody about placing my retarded, mongoloid child in an institution." The telephone operator said, "What do you want to do that for, Dearie?" and talked with and counseled the mother for fifteen minutes over the telephone. The mother changed her plans and the child was subsequently admitted to a regular class in public school. It was the telephone operator, who, lacking professional training, was able to ask, "What do you want to do that for?" I sympathize with the parents; this is a problem we have to solve. But parents are not blind; if they discover what other children have experienced in community residences, their resistance is going to slowly melt away.

Assuring Quality of Care

What we have to solve, and where you can help from your experience with the educational system, is this question of quality assurance. How can we be certain that, if we have federal funds channeled toward the community, there will be quality of care?

Coalitions and action committees have a role to play in assuring quality of care. How to monitor, how to work together with official people to get this quality assurance, how to train monitors, whether or not to develop within the profession a monitoring mechanism—these are urgent questions about which we need to think.

I listen carefully when people say, "How can you make sure that if we decentralize the care of all these people and place them in the community, there will be good quality of care?" Let me say, from the bottom of my heart, that the care could not be worse than it is in the institutions. Certainly, we have an obligation to ensure that the new answer will meet standards that are compatible with our beliefs.

Technical Assistance for Parent Programs

As discussed in the last issue of **Coalition Quarterly**, "Recent Developments" (Vol. 3, Number 1), the Education of the Handicapped Act Amendments of 1983, P.L. 98-199, require that a specified percentage of the annual education appropriations be set aside to support parent-to-parent training and information projects throughout the nation, and to provide technical assistance for establishing, developing and coordinating such programs. A new national project, the Technical Assistance for Parent Programs (TAPP) Project, coordinated by the Federation for Children with Special Needs, has been funded to satisfy this requirement for technical assistance.

Through the regional structure of the National Network of Parent Centers, the TAPP project will use experienced leaders of parent-operated organizations to provide technical assistance to groups that train parents to:

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- "better understand the nature and needs of the handicapping conditions of their child;
- "provide followup support for their handicapped child's educational programs;
- "communicate more effectively with special and regular educators, administrators, related services personnel, and other relevant professionals;
- "particiapte in educational decisionmaking processes including the development of their handicapped child's individualized educational program;
- "obtain information about the programs, services, and other resources available to their handicapped child, and the degree to which the programs, services, and resources are appropriate; and
- "understand the provisions for the education of handicapped children as specified under part B of the Education of the Handicapped Act."

Initially the TAPP Project will focus primarily on assisting the parent training and information projects around the country which received funds this past summer from the Office of Special Education Programs, U.S. Department of Education. Cynthia Gilles, project manager, states that another high priority of the project is to provide assistance to groups from minority and other underserved populations.

Direct delivery of technical assistance will be provided regionally through the following five regional centers:

NORTHEAST REGION
New Hampshire PIC (Parent Information Center), P.O. Box 1422, Concord, NH 03301. Telephone (603)224-7005. Judith Raskin, Director; Carol Hogan, Technical Assistance Coordinator.

MIDWEST REGION
PACER Center (Parent Advocacy Coalition for Educational Rights), 4826 Chicago Avenue, Minneapolis, MN 55417. Telephone (612)827-2966. Paula Goldberg, Director; Polly Edmunds, Technical Assistance Coordinator.

NORTHWEST REGION
Washington State PAVE, 1010 South "I" Street, Tacoma, WA 98405. Telephone (202)272-7804. Marty Gentili, Director; Jo Butts, Technical Assistance Coordinator.

SOUTHWEST REGION
TASK (Team of Advocates for Special Kids), 180 E. LaVeta Avenue, Orange, CA 92666. Telephone (714)771-6542. Raylene Hayes, Director; Kathy Boka, Technical Assistance Coordinator

SOUTH REGION
PEP (Parents Educating Parents), 1851 Ram Runway, #104, College Park, GA 30337. Telephone (404)761-2745. Mildred Hill, Director; Carla Putnam, Technical Assistance Coordinator.

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A Journal of the NATIONAL NETWORK OF PARENT CENTERS

Parents of Children with Disabilities as Collaborators in Health Care

by Betsy Anderson

***Betsy Anderson** is a founding member of the Federation for Children with Special Needs and currently serves as the Director of Health Issues for the Federation. A pioneer in the promotion of parent/professional collaboration, Ms. Anderson's involvement in issues concerning children with disabilities and chronic illnesses began with her oldest son Michael who was born with multiple handicapping conditions which has necessitated continuous involvement with health care systems. During the past six years, she has worked closely with state, regional and federal health agencies, state and federal departments of education, private hospitals and parent organizations to address issues of concern to families. Her work on behalf of chronically ill children in Massachusetts has helped develop models and options for children nationwide.*

Inside . . .

Parents and Professionals: the Essential Partnership for Families in Crisis
by Ann Rogers Oster

SKIP
Sick Kids (need) Involved People
by Karen A. Shannon

Legal Issues and Interpretation of P.L. 94-142
by Reed C. Martin, J.D.

Federal Initiatives on Home Care Under the Medicaid Program

The role of parents in the care of their children with special health needs has been changing rapidly, largely in response to developments outside of health care. Federal legislation that has given parents a greater consciousness of their role and increased their legal rights in the special education of their children has been a major influence. This evolution has been complemented by a greater understanding on the part of the medical community of the value of parental involvement.

In assessing the role of parents in health care, this article notes significant forces influencing role changes, with special consideration to movements in our society which have had a major effect on the overall expectations and roles of individuals with disabilities and parents. Next, the traditional roles of "patients" and parents in health care are considered, along with recent changes. The opportunity for and the emphasis placed on consumer involvement in the overall health system can encourage or discourage participation by families and individuals with disabilities. This article looks at some of the messages conveyed by systems, and closes with a list of benefits of active involvement to professionals, to parents and to children with disabilites.

Disability Movement

Parents of children with disabilities and adults with disabling conditions first began to form self-help groups in the United States in the early fifties and sixties. In an attempt to secure rights and services for persons with disabilities, families and people with handicapping conditions joined together to use political processes. Since people with disabilities everywhere had been denied even the most basic opportu-

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Coalition Quarterly

This issue of **Coalition Quarterly** focuses on parent/professional collaboration in health care for children with chronic illness and disabilities. Parents of children who have had significant involvement with health care systems share the perspectives gained from their personal experience — perspectives buttressed by professional involvement with families of children with similar problems and with organizations devoted to serving that population.

Betsy Anderson examines the emerging role of parents as consumers within the context of recent social, legal and philosophical trends. Next, **Ann Oster** discusses the emotional needs of parents in crisis, especially their need for peer support and information. **Karen Shannon** describes how one family's commitment to home care for their daughter led to the development of SKIP, a national organization devoted to making home care a possibility for other children with similar needs. Accompanying Karen Shannon's article is information prepared by the Region I Office of the Federal Health Care Financing Administration describing federal initiatives supporting home care for certain children. In the final article, **Reed Martin** provides an update of the significant legal issues affecting the education of children with special medical needs, focusing especially upon their right to inclusion in the public schools.

Although there is an overall emphasis on the issues confronting parents and families with children who are medically fragile, the application to the broader population of children with chronic illnesses and disabilities is clear. SKIP's commitment to home care for children with complex medical needs, for example, is helping to design workable solutions to problems of home care that can be studied as models for home and community based programs.

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nities — education, transportation, public access, jobs, housing — there was much to be gained.

Initially, incremental gains were made for specific categories of disability, often at the local or state levels. These gains might have included an education program for children who were deaf, provisions for curbcuts for wheelchairs, or a vocational training program for mentally retarded persons, for example.

By the late 1960s, groups organized around specific disabilities began to realize that many of their needs were common ones that might better be met by working together for broad far-reaching reforms. Thus, the decade of the 1970s gave rise to state and national coalitions of disability groups, united with a shared goal of expanding rights for all people with disabilities.

The efforts of broad coalitions of parents, adults with disabilties, and committed professionals resulted in the passage of revolutionary federal laws. The two most significant of these laws, Sections 504 of the Rehabilitation Acts of 1973 and the Education for All Handicapped Children Act of 1975 (Public Law 94-142), became effective in 1977. Section 504 provides that "no... qualified handicapped individual... shall solely by reason of his handicaps, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." P.L. 94-142 guarantees a "free appropriate, publicly funded education" to all handicapped children in the United States. Many other state laws and local ordinances were passed around this same time, expanding and enhancing rights and opportunities for persons with disabilities.

Consumer Movement

The consumer movement, which has had a powerful impact on our society over the past twenty years, has sought to protect the rights of consumers by asserting that systems should be accountable and that those for whom they are designed or who are affected by them should play a part in their development and evaluation. At conferences, participants are expected to complete evaluation forms; on airplanes, passengers are asked to comment on the service; at home, calls or letters request opinions on anything from preferences for televisions shows to views on political issues. Many people serve on neighborhood and town committees; in human service agencies, nearly every program has an advisory board which requests citizen input. Procedures to ensure parent and consumer involvement were mandated in the new special education and civil rights laws mentioned earlier.

It is not surprising, therefore, that people with disabilities and their families have taken the initiative to

give feedback and to suggest ideas in medical settings and care.

Expanding Effects of Change

Change in one system can cause change in another system in a number of ways until eventually it is felt in every aspect of society. Along with the new laws came a sense of entitlement; people also began to internalize a new and different view of disability. A sense of empowerment resulted from participation in the struggle to create change and those who participated in the struggle began to employ their visions and expertise to new issues and systems.

Parents, who under federal educations laws, have the right to review school records, including medical evaluations and reports, and to participate in planning in special education settings may assume they have the same rights in other settings, such as health care. There is an assumption that parents and individuals with disabilities have a right to basic information about themselves or their children, and that they can participate meaningfully in planning and decision making.

People who use various special support systems have grown much more knowledgeable about the impact of these systems on their lives, and have generally raised their expectations of them. Now, for example, the belief that all children shotild go to school has expanded to include the expectation that children should benefit from education, and that students should be prepared for work or for further education.

Increasingly, doctors and other health professionals have found themselves responding to questions raised by parents and educators, questions not traditionally regarded as part of the medical domain. How many classes shall Tom, who has a cardiac problem, take before needing to rest? Should Ann, in a wheelchair, ride to school in a van with a lift, or should she be learning to transfer? What should be the components of a sex-education program for Susan, a teenager with Down syndrome?

Normalization Principle

These questions are also reflective of how changing attitudes and expectations for children with handicaps and chronic illnesses have become part of the social fabric. More and more it is assumed that even those children with serious disabilities, medical problems and developmental delays will attend school, camp, take music lessons, play with friends, go on trips, and live at home with their families. In short, the expectation is that people with substantial disabilities will live lives very similar to those of their nondisabled peers.

Much of this underlying change in attitude had its origins in the philosophy of normalization, first promulgated in Sweden by Bengt Nirje and later popularized in this country in the 1960s by Wolf Wolfensberger. While that movement was initially articulated on behalf of mentally retarded individuals living in institutional settings, its applicability to many other disenfranchised groups became readily apparent.

The expectation for full participation in life for persons with disabilities that is implied in the philosophy of normalization has placed pressures on health systems. Now, even parents of children with serious disabilities consider caring for them at home. Families whose children have complex medical needs for parenteral nutrition, kidney dialysis, intravenous medications and oxygen, to use just some examples, are learning the necessary medical procedures and care which allow them to bring their children home from hospitals. At the same time, they are working with other parents and professionals to develop adequate funding and community support systems. Coinciding with this trend are two other importatnt factors: (1) Recent advances in medical technology now make it possible for many more children's lives to be sustained, although with more serious medical complications. (2) Efforts to shorten in-hospital stays in order to lessen the high costs of hospitalization are increasing.

In other instances, parents, often in conjunction with professionals, work to extend hospital visiting hours, expand play activity programs, and instigate a variety of changes to make hospitals more responsive to the needs of the "whole" child and family.

Changing Role of Family

Along with changing social expectations that have dramatically changed the roles of families in the care of their children, families must learn to deal with very complex systems of health and social services. Families and professionals together must look at the entire network of service systems and must assess the resources and constraints of the network components, many of which have overlapping responsibilties for children with disabilities.

Additionally, there are many more providers of services on the scene. Physical therapy may be delivered in a hospital, in a school or at home, by private therapists, the visiting nurse association, an early intervention or rehabilitation program; or therapy may occur in another form such as adaptive physical education or therapeutic recreation. This means that families are likely to receive information and advice from a variety of people whose views may not always coincide.

It is the parents of a child who are the link among the specialists and the only people who see the child in all settings over time. Therefore, parents must be prepared to assume the role of providing the overall management to coordinate the efforts of these many

specialists and the needs of the child within the context of the family.

Further, there is a sense that medical care and treatment, while critically important at some moments, may have less significance at other times. In some sense, the "limits" of medicine are most graphically seen with children and adults who will never be cured. The tendency of health care has been to view and treat in the context of acute care, with a goal of curing the patient. Now, many families and disabled adults reject or at least question that view.

The charge to medicine is to be more humane, to place greater emphasis on those aspects of a person which are not disabled, to add coping and caring skills to their curing skills. To some extent, people determine for themselves the significance that disability will play in their lives. The correlation between the extent of disability and the quality of life is not a given.

Changes in Health Care

Some of the most striking transformations that have occurred in health care have been, not in the area of disability, but in childbirth and obstetrics. Women, while refusing to accept the "sickness" model of pregnancy, have made, in the process, considerable change in the way childbirth and deliveries occur. "Preparation for childbirth" classes, fathers being included in the delivery room, childbirth with minimal or no anesthesia, in settings which range from the music and low lights of the Le Boyer method, to home-like "birthing centers," to birth at home, are all acknowledged today.

In Massachusetts in 1975, Children in Hospitals, Inc., a parent-professional organization concerned about the separation of children from their parents during hospitalization, began surveying major hospitals in the state regarding their policies of visiting hours and rooming-in. What was originally viewed as a radical action, publicizing hospitals' own statements in such a way that families could compare them, is now readily accepted and has been adapted for use by groups in many parts of the country. The original survey has been expanded over time to include questions on related issues.

Access to medical information is another area that has undergone a great deal of change. In the past, anyone wishing to obtain information on health care or medical issues would have needed access to a medical library. While this is still true of much technical material, any general bookstore can attest to the tremendous increase in the number of books available on health care and the human body. From *Our Bodies, Ourselves,* to *How to Be Your Own Doctor (Sometimes),* to *The Patient Advocate,* all sorts of information and self-care books fill the shelves. These books are important not only because of the specific factual information they contain, but also because their very presence on the shelves communicates that these are issues the general public should know about and can understand. Now television shows such as those begun by Dr. Timothy Johnson describe a range of health problems and care, while others debate important medical ethical issues such as genetic choices, abortion, decision-making for newborns, in ways that help both to inform and shape public opinion.

Barriers to Change

Although, it is evident that consumers have made their voices heard in some areas of health care, those parts of the system dealing with chronic illness and disabilities have been slower to respond to such initiatives. Recent federal changes in the structure and functioning of the Title V Maternal and Child Health Crippled Children's Services programs have, for the first time, mandated citizen input into the development of state plans for the distribution of federal public health funds. Certainly, there are health professionals who have been able to include families actively and appropriately in health care without any special legislation or requirement. This inclusion has not been the norm, however, and such professionals have received very little recognition or reinforcement from the health system or their peers.

There is still a sense that health care lags behind other systems, especially education, in the importance placed upon consumer or parent input. One overriding explanation is that there is no real "system" of health care and no commonly understood entitlement by citizens. Medicine is generally in the private sector, while the majority of other services for individuals with disabilities and their families are in the public domain, a fact which may make unfair comparisons in terms of accountability and access. A 1984 study prepared for the U.S. House of Representatives Select Committee on Aging identifies the United States as the only major industrialized nation in the world that does not have a plan or system for delivery of health care.

Other possible explanations include the following:

- Change is difficult to achieve in any setting or systems. It is most likely to occur when there is impetus from within, a structure or context within which it can occur, and pressure from without, all happening simultaneously.
- The traditional view of the patient, and family by extension, has been as a passive recipient of care. That passive role, which may have a limited place in some acute care situations, is now recognized as inappropriate for those individuals with chronic

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Parents and Professionals
The Essential Partnership for Families in Crisis

by Ann Rogers Oster

Keynote Address at "Comprehensive Approaches to Disabled and At-Risk Infants, Toddlers and Their Families," a national conference sponsored by the Division of Maternal and Child Health, the Office of Special Education and Rehabilitation Services and the National Center for Clinical Infant Program—Washington D.C., December 14, 1984.

***Ann Oster** has been actively promoting and organizing parent-to-parent support and information services since the premature birth of her second child Nicholas in 1979. She organized Parents of Special-Care Infants, Inc., a volunteer peer counseling network which serves families in eight Baltimore area hospital special care nurseries, and is a founding member of Parents of Premature and High Risk Infants International, Inc. She currently serves as Special Projects Coordinator for the Maryland Committee for Children.*

Drawing upon her own experience as a parent and her years of working with other parents, Mrs. Oster's address discusses the emotional needs of parents who are coping with the crisis of the birth of a child with significant special medical needs. She examines how parents and professionals can best respond to those needs.

The entire text of this address is given below.

Two months ago, in Salt Lake City, Utah, Parents of Premature and High Risk Infants International, Inc., sponsored its first annual conference on Parent Care. This fledgling parent organization, running on the adrenalin and personal conviction of its members, had mustered the courage to invite Drs. Brazelton, Graven, Gorski, Mangurten and many other distinguished physicians, nurses and social workers to join parents in presenting research, clinical programs, and personal observations to an audience that we hoped would number 150.

There were a lot of surprises during the three days of the conference. When registration closed, nearly 370—professionals as well as parents—had come from as far away as Florida, Maine and Hawaii. There was an exhilarating sense of something big happening: the grassroots sprouting a new turf where parents and professionals who care about premature and at risk babies could talk with each other and learn from each other. Mutual respect and trust grew before our eyes as a hospital administrator advocated hospital funding for parent group coordinators because he felt that peer support was cost effective. Developmental pediatricians discussed the need to make the bizarre, high-tech environment of the NICU responsive to the human needs of babies, parents and staff.

It was an exciting notion that the technology centered approach to Neonatal Intensive Care is beginning to give way to technology supported care that focuses on human beings—not just because of altruism, but because hard evidence indicates that a humanized environment, and better informed, more empowered parents make a difference in the medical and developmental outcome of these babies.

Nearly as exciting was the clear implication that if parents and professionals could work together to generate this conference, there was no limit to what they could accomplish together for families.

Today, I have a similar sense of something big happening as we move closer to seeing disabled and at risk babies in the real life context of their families and their communities. That at a conference of this stature parents are included as experts on family relationships is an enormous step toward a partnership with limitless potential.

I am going to talk about the emotional needs of parents coping with the crisis of the birth and life or death of a potentially disabled child. And I want to examine how we—parents and professionals—can best respond to those needs. My own experience gives me both the advantage of a parent's view point, and the myopia of my own particular needs and circumstances. But my years of talking and listening to other mothers and fathers have taught me that although we may be able to generalize to the extent of predicting the likelihood of parental anger or fear or denial, the specific manifestations of those emotions are as varied as the individuals who feel them. The only way to discover what any collection of human beings needs is by listening to each one.

Five and a half years ago, when my son Nicholas was born prematurely, I felt more hostage than partner to a gang of powerful professionals who sustained his life and taught me the rules of a strange new variety of motherhood. I didn't question their competence in treating any of us: my husband and I needed to believe that someone had wisdom in this situation that had spun our lives out of control and made us

wonder who we were and whether we were any good. The individuals stand out who helped me begin rebuilding a sense that I was worth something: the nurse who sat and talked with me when she had time, and loaned me a nursing text when I was frustrated by my ignorance; the child life teacher who asked how I was doing and then sat down to listen as I told her; the physical therapist who celebrated Nick for what he **could** do instead of defining him by his disabilities.

We were given very little information, and our skills training consisted more of prohibitions than positive action.

But so many of our contacts with professionals were frustrating or destructive to our self-esteem. We were given very little information, and our skills training consisted more of prohibitions than positive action. So we became expert at handwashing and technical jargon about blood gasses and electrolytes. Instead of being instructed about how to deal with Nick's developmental immaturity, we were encouraged to play the strange nursery game of pretending he was a normal baby. One day I asked a nurse how this experience affected mothers and babies in the long run. She told me that a few mothers were abusive, but most were just a bit overprotective. This was scant preparation for the blast of my own emotions over the next two years or so.

Information that Empowers

It is no accident that handbooks like Helen Harrison's *The Premature Baby Book* — written by parents — contain the kind of information that empowers: personal stories that illustrate and sanction the range of normal emotional reactions, definitions, rights, practical information, skills, facts about survival rates and what is known about prognosis. They don't offer protection from needless anxiety: parents know that parents of disabled and at risk babies are already anxious. What parents do offer other parents, through literature and friendship and organized peer support, is respect, with empathy and without the burden of clinical assessment — a precious resource for families in crisis. Ideally, the survival skills that only parents know are added to the rich expertise of professionals, who cure and teach and understand in a different way.

Mechanisms That Defend Us: Parents and Professionals

I have spent a lot of time since Nick was born examining how I felt and functioned as a mother when he was ill, turning over in my mind my relationships with professionals and my family and other parents. The most destructive factor during that period was my own difficulty in accepting my emotional reactions. Viewed more objectively, the mechanisms that defend us from dispair are logical. Guilt implies a comforting measure of control over a situation with no rational explanation. Anger defends us against blame. Emotional detachment numbs the fear of loss. Denial gives us time to learn new ways of coping, and the energy and humor to fight the facts in ways that sometimes generate new services and better futures for our children.

Those mechanisms were logical and necessary, but at the same time they insulated me from the people that I loved as well as from the painful facts of Nicky's illness. I wondered what was wrong with me, and I was too vulnerable to the judgements of the professionals who cared for Nick to ask for their help directly. I pretended to be more competent than I felt, and missed opportunities for help. I was defensive and demanding. I found fault with them for keeping a professional distance, thinking that if they would just become personally involved with us, they could provide the emotional support we needed.

I pretended to be more competent than I felt, and missed opportunities for help.

I was at an inservice once that dealt with infant death. I was sitting with my arms crossed, feeling irritated because a young unmarried social worker, rather than a parent, was speaking about what families need, when a nurse stood up and described her difficulty in coping with the death of a baby to whom she had become attached. She talked about how terrible it had been to go into the nursery the next day and see another baby in the crib. She made me see the magnitude of my demand for personal involvement. Like families, professionals must build the defenses that allow them to function in the face of human tragedy.

But families do need nurturing, and I am still angry five and a half years later at the professionals who were too insensitive or unskilled or human to give me what I needed. I am still mad at the doctor who said, when Nick was three days old, that I was in an awfully good mood for someone with such a sick baby. I am mad at the nurse who last week told another mother, who called at 11:30 at night to check on her 2 lb. 3 oz. son before she went to sleep, that she should call back in an hour, after rounds. The reason that these incidents are worth recalling here is not to prove that, like other people, professionals make mistakes, but because cumulatively their impact on families is profound, and if we care for babies we **must** meet the needs of families.

The Crucial Contact

When my daughter Bess was born, one of the unexpected benefits was membership in a community of parents who brought me chicken soup and nurtured me through the uncertainties of first time motherhood. Like me they were fallible, and like me they were available for listening to theories and insights and frustrations. We served each other as a base line for determining what was normal in ourselves and our children.

Once I made contact with other parents after Nick was born, I found the same remarkable resource. Other parents again provided me with a context — often just by listening without trying to reassure me; sometimes by reinforcing half-formulated plans of action; occasionally by confiding fears that mirrored my own. My own healing during Nicky's illness began with those parents. Finding them was surprisingly difficult. Through policies of confidentiality and professional territoriality, the system impeded our access to each other instead of encouraging this crucial human contact.

. . . a kind of prelude

Nick had chronic lung disease and was on oxygen until he was nearly a year old. He was rehospitalized several times after his first two and a half months stay in intensive care. One September day when he was just over a year old, he laboriously rolled himself to my dresser and reached up to play with the shiny brass drawer pull. I realized with a start that it was the first thing he had ever done that had reminded me of his sister Bess. Our questions about his development didn't begin to have answers until he was nearly two.

During much of Nick's early life the successes in coping with his problems belonged to professionals. Only the failures were mine. I hadn't had a healthy baby, couldn't seem to get him healthy, couldn't comfort him and, most painful, I didn't feel connected to him. I believed that I wasn't capable of doing him any good. I would like to read a poem that I wrote about surviving that period in our lives.

Bonding

Three years old on Tuesday,
think of it.
Two years ago I didn't know that I could love you,
precious boy.
I look at pictures of that year,
and see your smiles,
and wonder how I could have missed them then.
But we were both so needy that first year:
you for breath and growth,
I for the healthy son who would reflect my strength,
not demonstrate my failure.
I gave you all I had that year,
but numb with fear of doing you more harm,
I had so little.

Yesterday, looking at the pictures of your big sister
(I think you'd never thought before
that she was once so small),
serious and funny, you turned to me and said,
"She was little and when she was born,
she was very, very born."

No degrees of being born,
and yet for us there was a kind of prelude.
Three years since you were born,
Two since we began
the important part.

What Would Have Helped?

Like most other families, we were left alone, to sort out these complicated emotional issues. Two things would have helped: emotional support and information.

The most realistic way to decrease families' isolation is by providing them with access to their peers: the other families for whom this contact is part of their own healing.

Sometime after Nicholas had started nursery school I saw a grainy, black and white videotape that demonstrated what Dr. Brazelton calls the "irresistable responsiveness" of a premature baby. I almost cried while I watched as a 3 lb. preemie slowly followed a ball with his eyes, looked for the sound of his mother's voice, and with heroic effort, finally turned his head and even reached for her. A nurse practitioner had taught that mother to read the subtle clues that could have drawn me to my son so much earlier. It was a piece of information, a teachable skill, that might have changed the course of our lives.

Emotional support, too, was hard to come by. The cornerstone of this experience is loneliness. Our family was isolated by the physical realities of hospitalization and therapy sessions, isolated socially by an experience that few other families share, isolated from each other by the crisis itself, with each family member needing to curl up somewhere for comforting.

From Isolation to Membership in the Human Family

The most realistic way to decrease families' isolation is by providing them with access to their peers: the other families for whom this contact is part of their own healing. Peer support is just a fancy name for what happens in the office, and the grocery check out line, and the halls of nursery school: mothers and

fathers and business executives testing the accuracy of their own perceptions, and moving from the isolation of their own feelings into their context as members of the human race.

But it can be a complicated task for families of disabled and at risk babies to find their peers — particularly during the first few months or years when the future is a list of unimaginable possibilities rather than a clear diagnosis. Nick was nine months old before I met a mother whose baby had similar problems. I will never forget the incredibly intense feeling of recognition and kinship that I experienced during that hour-long talk in a hospital cafeteria. And later, as our parent group flourished, I saw so many other mothers and fathers experiencing the remarkable sense of connection that had kept a group of strangers talking in a hospital parking lot until midnight after our first meeting.

Sharing Resources

As parents and professionals we can best accomplish the difficult job of meeting families' needs by utilizing each other as practical human resources. Parents developing literature or programs containing medical or educational information must turn to professionals for guidance. Professionals developing services for families must draw on the special expertise of families. A few years ago, I saw an intensive care nursery parents booklet developed by nursing staff. The project had been undertaken generously as a service to parents, and the booklet contained good information, but it began with a list of prohibitions and its terminology "allowed" visiting, rather than encouraging it. Exactly contrary to its purpose, it subtly reinforced the powerlessness of parents.

Helen Featherstone said that when parents tell about discovering their children's handicaps, their descriptions invoke images of cataclysm. As we care for these families we must respect the magnitude of their task. As they rebuild their lives, we must aid them in ways that increase their strength and build their self-esteem. It behooves all of us to set out from here determined to develop a forum where parents and professionals can share the valuable and hard-won knowledge that each of us possesses. □

For more information about parent support contact:

Parents of Premature and High-Risk
Infants International, Inc.
Maureen Lynch, Executive Director
33 West 42 St., Room 1227
New York, NY 10036
(212) 869-2818

Parents as Collaborators

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disabilities whose involvement with the medical system will generally be lifelong.

- Health professionals are trained to help by curing. Therefore, by providing the answers and the care, by doing the thinking and the worrying, by making the hard decisions, an honest mistake may have been made that this all-inclusive role benefitted patients and families. Instead, this total assumption of responsibility has created dependency and has discouraged individual action and thought. Now, parents and consumers, with the impetus gained from being recognized as partners with professionals in other settings, sometime experience frustration and even anger at being treated in ways they may view as patronizing.
- Perhaps one of the most serious obstacles to change is the very narrow view of disability which medicine has held. By discounting the many other aspects of disabled peoples' lives, the medical field has been able to keep its sphere quite limited and specific. While this has had some undeniable benefits, doing so has necessitated that the focus remain almost entirely on what is "wrong," and often cannot be cured. Consequently, other approaches, resources, and supports which could ultimately help people live satisfying lives have been considered at best of secondary importance and at worst ignored.
- There are few laws that give rights to consumers in the area of health care. Section 504 of the Rehabilitation Act of 1973 is obviously an exception. Laws governing public systems usually require access to public records and meetings for informing citizens and eliciting their input. In lieu of such laws, the medical system is bound by requirements of "Informed Consent," an area of potentially great significance, but one that is generally not well understood by patients and their families.
- Even with changes occurring today, the medical system remains one of the most hierarchical of systems. Such a structure is not one that readily lends itself to change. In fact, few medical settings have policies or guidelines concerning regular consumer involvement, unlike nearly every other public system, and many private service agencies.
- Finally, a situation not limited to the health care system, has been the lack of mandates or incentives for the many service systems which impinge upon children and families to coordinate and collaborate their activities.

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SKIP
Sick Kids (need) Involved People

by Karen A. Shannon

***Karen A. Shannon** is the founder and national executive director for SKIP, Inc. [Sick Kids (need) Involved People], a non-profit organization of families and public and private health professionals devoted to supporting and facilitating home care for technology-assisted children.*

SKIP developed from the Shannons' personal experience in creating a home care program for their daughter Erin who has required the use of a ventilator since shortly after her birth. SKIP has grown to include chapters nationwide. Mrs. Shannon's commitment to home care for medically vulnerable children, which began with her struggle to bring Erin home from the hospital, has led her to work closely with both state and national Departments of Public Health and Education to establish models for home care. As a nationally recognized parent leader, she is a frequent featured speaker at conferences and serves on forums devoted to issues of home care and health financing.

"I want to take her home, to love her and care for her, but how? I can't do it alone."

This longing and this question formed the basis for our organization. SKIP was born in November 1979, out of the triumphs and tribulations of bringing my daughter Erin, who was suffering from a rare respiratory condition, home and the numerous challenges we faced in keeping her home. It grew out of a caring, committed partnership between one family and one doctor, working together to make a normal home environment possible for Erin.

Erin's life was made possible through dramatic breakthroughs in modern technology. This same technology which gave Erin her chance for life and growth initially continues to play a necessary role in her continued survival. A similar dependency on medical technology is true of many chronically ill and high-risk infants and children across our country — children who represent a new category of disability, a category created by technology.

As families with circumstances similar to ours learned of our successful efforts to care for Erin at home, they began to contact us for advice. They wanted to know what preparations were needed, what resources were helpful, and how to access them. Along with the help of Erin's physician who had been our advocate and partner throughout, her respiratory therapist, and a small group of nurses, we developed SKIP, a formal, organized approach to meeting the needs of these families.

Karen Shannon and her daughter Erin.

Now, a national movement is underway to develop a regionalized system to prepare families and communities to care for children who are assisted by technology at home or in the least restrictive environment. A handful of families in the nation have succeeded in bringing their medically intensive care sustained children home. They have developed strong complete networks of support drawing from all facets of the medical, business, social and religious aspects of their own communities, relying on their own volition and initiative.

Importance of Collaboration: The Team

Knowing how to operate equipment and use the appropriate supplies is not sufficient preparation for providing home care for an infant who is dependent on technology and medical support. Successful adjustment to home care occurs when parents' psychosocial and instructional needs continue to be met. It is our responsibility as parents, health providers, community resource providers, and educators to work together to ensure success.

The quality and content of the collaboration between the hospital team, community resource providers, and parents can determine the success or failure of this specialized type of home care. The medical team instructs parents and home care providers on the infant's diagnosis, the proper use of equipment and

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FEDERAL INITIATIVES ON HOME CARE UNDER THE MEDICAID PROGRAM

prepared by the
Health Care Financing Administration
U.S. Department of Health and Human Services
Boston Regional Office

Historical Problem:

Medicaid fostered institutionalization because:

1. eligibility rules made certain individuals eligible for Medicaid while in an institution but not while living at home, and
2. services needed for care at home were not payable under the Medicaid program, i.e., respite care, day care (not medically oriented), chore services, homemaker services.

Short Term Solution:

Katie Beckett type of waiver addressed eligibility problem only.

Katie Beckett type of waivers were instituted as an interim solution to the eligibility problem to allow the States time to develop and implement Section 1915(c) of the Social Security Act, home and community based services waivers, explained below. A Katie Beckett type of waiver involved a decision by the Department of Health and Human Services (HHS), under existing authority contained in the law and regulations for the Supplemental Security Income (SSI) program, not to apply the usual deeming rules of the SSI program because it would be inequitable to do so. Under usual deeming rules, the income and resources of a spouse, or parents in the case of a child under age 18, are deemed as available to the individual or child applying for Medicaid if living in the same household. An institutionalized individual is considered not to be living in the same household as the individual's family; therefore, the family's income is not deemed to the individual, thus making him or her more readily eligible for Medicaid.

This information was prepared for dissemination at the "Home Care Issues for Children with Serious Medical Needs Conference" held in Boston on March 1, 1985. The conference provided an opportunity for parents, health professionals, state and federal financing administrators, and private insurance representatives to identify problems, explore solutions, and develop options which will truly support children at home. The conference was co-sponsored by the Federation for Children with Special Needs and the Region I Office, Public Health Services, U.S. Department of Health and Human Services.

An HHS Board was established to review States' applications for waiving normal SSI deeming rules in individual cases. Regulations published on 6-4-82 and revised 2-15-84 spelled out the conditions that needed to be satisfied for the Board to approve a Katie Beckett type of waiver:

a. deeming led to Medicaid ineligibility;
b. eligibility in non-institutional setting would yield Medicaid savings; and
c. quality of care would be maintained.

The Board stopped accepting new applications as of 12-31-84. Previous determinations will remain in effect, as long as the conditions are satisfied. Applications pending as of 12-31-84 will be considered. New cases should be handled by the States through Section 1915(c) waivers, particularly the model waiver.

Long Term Solution

1. **1915(c) home and community based services waiver** (includes the model waiver) addresses both the **eligibility** problem and home care **services** problem.

Section 1915(c) home and community based services waivers are sometimes referred to as Section 2176 waivers because Section 1915(c) was added to the Social Security Act by Section 2176 of the Omnibus Budget Reconciliation Act of 1981. Section 1915(c) of the Social Security Act allows a State, under a waiver approved by the Secretary of HHS, to provide home and community based services to individuals who would otherwise require nursing home care that would be paid by the State's Medicaid program. In addition to paying for traditional non-Medicaid services, a Section 1915(c) waiver allows a State not to deem a family's income to those home care clients who would qualify for Medicaid if institutionalized but would not qualify while living at home if the usual SSI deeming rules were applied.

Model Waiver: preprinted Section 1915(c) waiver application that can be used by the State under the following conditions:

a. no more than **50 blind and disabled children and adults** can be served per model waiver request;
b. some of the blind and disabled children and adults involved in the waiver must need a waiver of the usual SSI deeming rules to qualify for Medicaid while living at home; and

c. at least one home and community based service must be provided.

The model waiver is seen as the main vehicle for dealing with the Katie Beckett type of waivers now since the Board is not accepting any new applications. The model waiver was developed to expedite review of waivers involving smaller populations. It can be used for just one individual. The application form considerably simplifies the process of requesting a Section 1915(c) waiver.

Model waivers, as all Section 1915(c) waivers, must be acted upon by HHS within 90 days or they are automatically approved. HHS has one opportunity to request additional information. HHS then has 90 days from receipt of the additional information to render a decision.

2. Medicaid Coverage of Home Care for Certain Disabled Children, Section 1902(e) of the Social Security Act, added by Section 134 of the Tax Equity and Fiscal Responsibility Act (TEFRA) of 1982, addresses **eligibility** problem only.

A State can choose to amend its Medicaid plan to cover certain disabled children who satisfy the following conditions:

a. the individual would not qualify for Medicaid at home under the usual SSI deeming rules, but would qualify for an SSI or State supplement payment and, therefore, Medicaid in certain States if he/she were in an institution;
b. the child requires a level of care provided in a hospital, skilled nursing facility, or intermediate care facility, including an intermediate care facility for the mentally retarded;
c. the child can be appropriately treated at home (outside of an institutional setting); and
d. the cost of treating the child outside the institution does not exceed the institutional costs.

This option does not provide for any additional services to be provided to the disabled children; the children are made eligible to receive the services provided under the State's regular Medicaid program only. □

The federal initiatives described above contain provisions permitting states to offer, under their Medicaid plans, coverage for home care services to certain children with disabilities who would otherwise be institutionalized, even though a family's income and resources exceed the state's normal financial eligibility standard. Since Medicaid is a state administered program, however, each state has the option to implement the waiver program and to determine the type of waiver program it will put into place.

For more information on a state's waiver program, contact the state agency that administers the Medicaid program. If there is a question about the appropriate agency, contact the Federal Regional Office of the Health Care Financing Administration.

Boston Regional Office
John F. Kennedy Federal Building,
Room 1309
Boston, Massachusetts 02203
(617) 223-3697

Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont

New York Regional Office
26 Federal Plaza, Room 3811
New York, NY 10278
(212) 264-8517

New Jersey, New York, Puerto Rico, Virgin Islands

Philadelphia Regional Office
3535 Market Street, Room 3100
Philadelphia, Pennsylvania 19101
(215) 596-6828

Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia

Kansas City Regional Office
New Federal Office Building, Room 235
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Kansas City, Missouri 64106
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Denver Regional Office
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SKIP
Sick Kids (need) Involved People

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supplies, infant assessment tools, cardiopulmonary resuscitation, and methods for documenting events. It helps identify and address psychosocial problems, including fears and misconceptions. In essence, the team provides the training and support needed to enable parents to willingly and appropriately assume responsibility for their child with chronic/acute illnesses.

The team's goal is to help the families understand several realities of home care:

- First, that their infant, faced with a potentially long-term illness, could suffer from an acute episode such as severe respiratory distress, leading to possible death or damage at any moment.
- Second, in administering their own special "Intensive Care Unit," families must cope with operating requirements and limitations of medical devices, supplies and services, and know how to safely adapt to these limitations.
- Third, the family must receive and welcome the Medical/Resource/Support Team into their life as their infant's "LIFE LINE."
- Finally, the family must assume direct responsibility and understand the consequences of this responsibility should their infant require crisis intervention in the home.

This challenge, complete with many rewards as well as heartaches, represents a responsibility and an acceptance that requires major changes in lifestyle and values to achieve the goal of "Intensive Home Care." It is critical that what is asked of each parent reflects the realities of Home Care Team participation. This endeavor **cannot** be achieved alone.

Components of Successful Home Care Placement

In addition to the overall importance of team collaboration, successful home care placement of technology-dependent children requires several interrelated components.

- **Strong family commitment.** Commitment of the parents to each other as well as to the child is very important.
- **Thorough discharge planning.** A home care package should recognize the concept of on-going family adjustment. You adjust, but you must reaccept your situation every single day, and some days you just cannot do it. That is why respite care, counseling and parent support groups are essential. After parents have had their child home six months, they participate in a parent-to-parent network.
- **Team approach to planning and follow-up.** Although we see the physician as the primary focal point to make home care work, active multidisciplinary participation is vital.
- **Nursing care.** Nursing care is the backbone of the home situation. It is neither fair nor realistic to expect parents to care for their ventilator-dependent respiratory failure child indefinitely on a 24-hour, 7-day a week basis.
- **Adequate, flexible funding.** To make home care work we must recognize that some families can cope with fairly minimal supports, while others may require high levels of support and assistance. Flexible funding is vital because the family situation changes over time, and home care arrangements need to adapt accordingly.
- **Quality assurance.** Monitoring is needed to assure that the services and the products being delivered in the community are of the highest standards possible.

SKIP's Role

SKIP provides education, peer support, and other resources to assist families who have decided on home care for their hospitalized child by preparing and maintaining a network for the safe and controlled intensive care management of the child. SKIP promotes every child's right to an enriching, meaningful life, in as normal a life style as possible, preferably within the natural environment of the home. Our objectives include:

Education: Develop materials to meet the educational needs of the child/family, health care professionals, and community agencies, in addition to increasing public and professional awareness about specialized pediatric home care issues.

Resource: Identify the resources that are available to families and providers, and assist in the expansion or development of new resources.

Family Services: Assist families in identifying and accessing resource services, and providing family support.

If SKIP can be of assistance in developing your home care program or in seeking funding alternatives for these children's home care plan, please contact the National Headquarters of SKIP, 216 Newport Drive, Severna Park, MD 21146, (301) 647-0164.

With more and more children surviving illness and traumatic births, SKIP continues to build a partnership of care to ensure that new specialized home care families will survive and grow as a family, together at home. □

Legal Issues and Interpretation of P.L. 94-142

by Reed C. Martin, J.D.

The following address by ***Reed Martin, J.D.,*** *was delivered at the "Home Care for Children with Serious Handicapping Conditions" conference by the Association for the Care of Children's Health and the Division of Maternal and Child Health, Public Health Service, U.S. Department of Health and Human Services held on May 27, 1984, in Houston, Texas. This address is exerpted from the published conference report with the permission of the Association for the Care of Children's Health and the author.*[1]

Reed Martin currently serves as staff attorney for the Texas Developmental Disabilities Protection and Advocacy agency operated by Advocacy, Inc., in Austin. He aslo serves as consultant to the Education Resource Network, the parent training and information program operated by Advocacy, Inc.

I am an attorney who has been working with parents of children with disabilities for 15 years. Two years ago my son was in an automobile accident. He was brain-injured, and although he has recovered remarkably, he has chronic health problems and needs medication. I understand well the issues involved with educating a child with disabilities, because I am never sure when my son might have to be absent from school. This situation can be very unsettling, not only for the parents but also for the teachers, and as we see in the following examples, the issues surrounding education for the handicapped have been unsettling for the courts.

Many of the issues that you face may not only have already been addressed by federal courts, but also may have been decided in your particular jurisdiction. You may not know about it, the school may not know about it, the hospital may not know about it, and even many attorneys may not know about it. Let me illustrate the extent and nature of the problem by quickly describing three cases.

Tatro Case

The Tatro case, which originated in Texas, was argued in the Supreme Court on April 16,1984. It concerned a girl with spina bifida who is slightly disabled and who needs clean intermittent catheterization. She is now eight and a half years old and is capable of self-catheterization, which makes the whole case a moot issue; however, the case originated five years ago when she still needed assistance. The school district refused to take the responsibility, claiming it was too risky. After the school's initial victory, the parents won their appeal at the district court level and twice at the circuit court level. In spite of clear legal mandates that related services must be provided, the school appealed to the Supreme Court.

As we worked with the Tatro Case, we were impressed by the incredible diversity of policies with regard to such matters. A school district next to that of the Tatro's, for example, catheterizes 400 children daily in their public schools; another school district, however, has recently threatened to fire a school nurse if she continued to catheterize a child. They feel that such a child imposes too great a liability or burden on the system. It was also evident, from their questions while arguing the Tatro case, that the Supreme Court was unclear as to the needs and capabilities of children with disabilities and the role of the schools in meeting them, especially with regard to the type of medical problems children are bringing to public schools today.

In so doing, the court emphasized, with great wisdom, that the chronic medical needs of a child must be balanced with the overwhelming need and right to associate with his or her peers.

On July 5, 1984, the Supreme Court ruled unanimously in favor of the right of students to attend school and receive any needed services. This ruling greatly expanded the definition and scope of related services. The court rejected the notion that medical needs, excess costs, or staff liability should impede school attendance. They affirmed that children, under P.L. 94-142, could receive any and all services needed to reach, enter, exit, or stay in school.

Espino vs. Besteiro

Espino vs. Besteiro, which also originated in Texas, concerned a boy who had been seriously hurt in an automobile accident. He used a wheelchair, and his body could no longer control his skin temperature due to injury to his hypothalamus. As a result, he had to be kept in an environment with a temperature range of about 15 degrees. The school decided to solve the prob-

[1] *Home Care for Children with Serious Handicapping Conditions: A Report on a Conference Held May 27, 1984, Houston, Texas.* Linda Harteker, editor. Washington, D.C: The Association for the Care of Children's Health, 1984.

lem by putting him in an air-conditioned plexiglass cube five feet square. The court disagreed with the school's position and ordered that the boy be placed in an air-conditioned classroom where he could interact with classmates. In so doing, the court emphasized, with great wisdom, that the chronic medical needs of a child must be balanced with the overwhelming need and right to associate with his or her peers.

Dorr Case

The Dorr Case was decided in April, 1984, by the Ninth Circuit Court of Appeals. It concerned a girl who needed suctioning, and since she could usually anticipate the need, it rarely caused a problem. That the tube might become dislodged was a concern because repositioning the tube required a higher standard of care and immediate attention. The school organized a meeting of all the staff who would come in contact with this child. Everyone in her normal environment — teachers, cafeteria employees, custodial staff — was asked to attend. It was a disaster. Teachers filed grievances with their appropriate union officals and refused to have anything to do with this child. Because she was barred from any admission to the public schools, she has been in a private school at public expense ever since.

Many children, however, can be in a totally normal academic program and still fit the special requirements; the asthmatic child, mentioned earlier, is a perfect example.

The Ninth Circuit Court was critical of the school's failure to explain its reason for denying her admission to a public school. The lesson to be drawn from this case is that we have to be concerned not only with planning the program, but also taking a look at teachers' and school employees' needs, concerns and fears. This decision is now in appeal in the United States Supreme Court.

The child has a right to be in school. A review of the legislative history makes it clear that attitudinal problems of this nature be addressed at the IEP meeting. In Senate **Report 94-168**(1975), Senator Stafford expressed the hope that " . . . teachers' participation in these IEP conferences will have a positive effect on attitudes of teachers toward the child . . . " Senator Randolph, in the same report stated, "The integration requirement of the bill [Senate Bill 6] requires inservice training of general and special personnel in dealing with the general problem of attitudinal barriers." In addition to such inservice being included in the IEP as a needed service, the IEP meeting itself was viewed as a problem-solving process, or inservice opportunity, for teachers, parents, school nurses, and others to confront such problems.

Forntunately, both P.L. 94-142 and the majority of the federal court decisions in such cases really do support common sense. The courts require that decisions about educational placement be made on an individual basis. Although in some cases they have required schools to accept children with communicable diseases, there is always specific attention to individual needs and circumstances.

The Integration Imperative

One of the most important things to understand is that we are dealing with the educational experience of these children, not their academic experience. The courts define education broadly, including social interaction. Most courts quote the Supreme Court decision, **Brown vs. Board of Education,** the 1954 school desegregation case, which reaffirms that we need integration not because a black child can only learn if he or she is sitting next to a white child, but that interaction and social integration are part of the experience of education. That can only happen if handicapped and non-handicapped children have an opportunity to learn together in the social setting of the classroom. Short-term hospital-bound or home-bound programs are certainly needed, but the long-term solution has to be maximum integration.

Many handicapped children do not need specially designed academic instruction. A lot of us think of special education as being only for children with mental retardation who need special academic programs. Many children, however, can be in a totally normal academic program and still fit the special education requirements; the asthmatic child, mentioned earlier, is a perfect example.

Importance of Individualization and Flexibility

Individualization is the key work in almost all these decisions. A school district that makes a categorical decision gets struck down in court. The individualization even extends to making changes in the length of the school day or the academic year.

The IEP meeting can set the stage for a cooperative effort to integrate a medically involved child into the school.

The thrust of P.L. 94-142 is to get every single child, aged 3-21, into the public school. Anything that interrupts that contact is disfavored. The individualization education program (IEP) must constantly be modified, taking into account new information and feedback. The child may get better, or worse; he or she may have to go back for chemotherapy, or may develop a memory problem. The program obviously has to be flexible.

The IEP meeting can set the stage for a cooperative

effort to integrate a medically involved child into the school. A minimum of three persons should participate in an IEP meeting: the teacher, someone from administration, and the parent. The teacher plays the most important role, because it is the teacher who indicates what he or she thinks would be appropriate for that child and whether it is feasible or whether additional resources will be needed. One teacher might say, "I can't deal with a child like that. I can't suction a child. I'd faint." If a child in the class dies, one teacher may be able to create a beautiful program built around the child's death for the other children in the class; another may be absolutely destroyed. Here is an example of a point where a teacher can say, "Hey, somebody's going to have to help me." Plans can proceed from there.

Role of State Education Agency

Finally, in interpreting P.L. 94-142, the courts have made it clear that the state education agency is in charge of coordination of education programs. In a number of cases which have gone to circuit courts, the courts have stated that Congress intended that single agency authority rest with the state education agency. If a child is somehow falling in the cracks among the health associations, crippled children's services, family services, social services, and human resources department, P.L. 94-142 very clearly says that the state education agency has the authority to coordinate that child's education program.□

Areas to Consider in Writing Individualized Education Plans for Students with Physical Disabilities or Special Health Needs

Developed by Betsy Anderson

1. Transportation: special equipment (seat belt, etc.), assistance from vehicle to school
2. Building accessibility and bathroom accessibilty
3. Occupational therapy, physical therapy, speech therapy
4. Medications: copy of prescription for files; who is to give them (student, nurse, teacher, other); side effects; where will they be kept?
5. Stamina
6. Positioning
7. Self help skills: feeding, dressing, toileting, need for assistance or training, or both
8. Special medical needs while in school
9. Special supplies or equipment: storage, anyone to be notified?
10. Backup medical support: who, where, what emergencies likely to arise?
11. Equipment needed for student to progress effectively: typewriter, computer, special grip pencils
12. Specially prepared curriculum materials: information to be taped or prepared in a different way
13. Art, music, other enrichment classes and activities: modification needed for inclusion
14. Physical education: regular program as is, modified, or adaptive physical education program; special equipment or staff required
15. Mobility and need for any assistance, regular provider and back-up person
16. Fire safety: a plan with indications of who is responsible and back-up person
17. Field trips: transportation, aide, any special comments
18. Extra curricular activities (this is a Sec. 504 issue): transportation, aide, any special comments
19. Home/hospital tutoring: is this needed now or will it be likely to occur; outline plan, even if only tentative

Parents of Children with Disabilities as Collaborators in Health Care

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What Consumer Involvement Communicates

Opportunities for consumer involvement may take many forms and the availability of these opportunities plays an important part in shaping consumer perceptions. Consider the messages which are conveyed, albeit unintentionally, to persons with disabilities and their families when they are denied the opportunity to be involved in their health care.

Interpretations of this type of exclusion may be:

1. The value of the contributions families and individuals can make is negligible.
2. Professionals know best and can handle it all. In fact, if they are not doing it, then it must not be important.
3. People with disabilities and their families get in the way and slow down the process. They are part of the problem, not part of the solution.

Value of Involvement

- **Knowledge gained through experience has value.** Personal experience has a value in decisions pertaining to one's own life. The sharing of ideas and findings that arise from personal experience may help others in similar situations and may prove

valuable to professionals in their dealings with others.

- **People can contribute to their own well-being.** People, even when they have substantial problems, as outlined by Norman Cousins in his book *Anatomy of An Illness as Perceived by the Patient*, are not completely helpless. Their contributions may be in terms of philosophy, attitude, or approach to life; or may be in the form of concrete suggestions or models, such as designs for a better ramp, making the "PKU diet" palatable, etc.
- **People can grow, develop, and adapt.** Initially, there may be questions about how much a person who is newly disabled or a family whose child has just been diagnosed as handicapped can contribute. What is important, however, is that they receive the message that over time the majority of people do cope and that everyone has the potential for growth. This assumption is vital to people's ongoing growth and developing self-concept.

  There are also times in people's lives when they may have less to contribut that at other times; even the most competent, articulate, motivated individual may have "down times."
- **The person with the disability and the family have the main responsibility to provide input and follow-through care.** If the level of expectation is low, then it is very possible that the outcome itself will be less than it might have been. If no one ever asks the family to comment, or provides an opportunity for such input, the family may stop considering other resources and begin to disregard their own thoughts, thereby cutting off an important source of creative problem solving. Taking responsibility for active, informed participation or wanting it to be a part of one's role has positive implications for carrying through with treatments and care. Noting and reporting results, making suggestions and modifications to professional recommendations, all are part of responsible participation.
- **None of us has all the answers.** People are affected by and respond to situations in unique ways; for any given problem there may be many solutions, or relatively few. Even when many solutions are possible, the particular circumstances may render some or all of them inappropriate. In one sense there are never too many ideas or solutions, and we should encourage thought from many sources.
- **We can learn from one another.** Whether parent, professional or a person with a disability, each of us possesses experiences, knowledge, and perspectives that can contribute to the overall picture. While some people can be expected to have large pieces of the puzzle, others may have smaller but particularly critical pieces. To develop or to encourage development of a system where participants are discouraged from seeking solutions from others, or where it is only permissible to seek answers from particular individuals, is to narrow unnecessarily the range of resources.
- **The system is accountable.** It is important that consumers know that the system does not merely pass out information and treatment without regard for whether these "work." Consumers need to know that there are reasons behind what is done or suggested; that indeed, on occasion mistakes are made, and that there are procedures for review and remedies for these occasions. In short, consumers need to know that the system works for them.
- **Individuals can incorporate new ideas and can (even) change systems.** Society is not limited to what it is today. Existing policies and practices can be critically examined to determine what works and what does not, what is worth keeping and what is not.

Benefits of Consumer Involvement

Consumer involvement can take many forms and can include a variety of activities. At its best, such involvement should be jointly designed with professionals and should include the possibility of participation by both individuals and groups, on personal as well as systems levels. The following are some important components of such a system:

- Ongoing provision of up-to-date, accurate information about self, care, services and entitlements
- Participation in the determination and delivery of services
- Preparation and training for the specific activities and roles to be carried out
- Process for giving feedback and evaluation of care and services
- Links to other caregivers and settings, including those outside of health care
- Links to adult service systems and, in particular, opportunities for adults with disabilities to participate in a variety of ways: as employees, as consultants, and in various advisory capacities
- Participation in the development of policies which govern the particular setting

Since professionals everywhere are likely to be overscheduled and overworked, it is possible that consumer involvement may be regarded as one more task. Some reasons professionals may want to involve consumers in their work include:

- It may be considered an important goal, in and of itself.
- It may overlap with other, already existing goals or tasks.
- It may, in fact, be required by state or federal law or by agency policy.
- It may provide benefits to professionals (personal,

political, public relations, advocacy, funding, etc.).

Benefits to Professional Staff

1. **Better planning and services.** Greater understanding of the issues for people with disabilities and their families leads to better questions and better answers.
2. **Compliance.** Families who understand the philosophy behind recommendations for care and treatment and who have had a role in the process may be more likely to carry out recommendations.
3. **More ideas.** Opportunities for discussing issues with others is apt to lead to more ideas or novel ways of approaching problems.
4. **Feedback.** Feedback from individuals with disabilities and chronic illnesses and their families is one way to improve services, and may also serve as important reinforcement to professionals for the jobs they do.
5. **Lack of need to be omniscient.** Including families in the search for solutions provides professionals with sense that this is a shared mission, not one for which they are solely responsible.
6. **Open forum.** Having a process and a place for discussing issues is one good way to develop relationships and deal with problems while they are still manageable.

Benefits to Families

1. **Legitimate role: partnership.** Most families want to actively participate because they care about their children and the services. Indeed, it is families who have had to take the initiative to establish their place in the system.
2. **Sense of growth, competence: chance to contribute.** Being regarded as capable of participating is an important message for families and for people with disabilities. Typically, families or individuals begin with little knowledge or sense of their own competence. This is an area where growth is particularly important.
3. **Carry-over information.** Families are responsible for transmitting information to a variety of people, including children themselves, grandparents, babysitters, school bus drivers, teachers, camp counselors, friends and neighbors, and others. Their need for solid information and understanding is an important one.
4. **Structured opportunities for feedback.** Since most people who receive services have a variety of feelings and thoughts about them, it can be frustrating not to have any formal way to channel them. Providing such opportunities reinforces in families the sense that their observations, thoughts, and experiences are important.
5. **Opportunity to discuss related issues.** Many services and issues affect families in significant ways. There must be room for reflection on the relevance and importance of these concerns to health care.
6. **Overall sense of system.** Families often receive care and information in fragments, with discussion limited to short term or immediate objectives. They are often left to imagine what lies ahead, with no concrete sense of how long-term issues will be approached. Immediate concerns still need to be addressed, but needless worry could be eliminated by discussing long-term care issues.

Benefits to Children

The role of children with disabilities and chronic illnesses may be difficult to pinpoint as it evolves over time. Nonetheless, parents and professionals can and should develop a program of care that recognizes children's needs and strengths and allows them control as well as the opportunity to participate.

1. **Knowledge of themselves.** Children need to be developing a sense of themselves, their bodies, their abilities, and their disabilities. Again, the better informed parents are, the better they can communicate information and issues to children in an ongoing way.
2. **Control, participation.** The goal for most children in health care should be to help them develop the ability and the confidence to make decisions and to carry out their own care to the extent that they are able. This includes the possibility of risk and failure, something all of us must experience.
3. **Expectations from adults.** It is important for children to know that their parents and the professionals who care for them expect that they will indeed be able to learn what will be needed.
4. **Self-esteem.** Children need to know that significant adults are interested in what they think and feel, that their concerns are important.
5. **Parental role models.** Parents serve as important role models for their own children. By taking active roles as partners with health and other professionals, parents help prepare children for their own roles later in life.

Forums for Discussion

An important assumption underlying the principles expressed here is the belief that parents and professionals require increased opportunities, both formal and informal, for communication and discussion. While interesting models exist in many human service settings, probably those in public education are the most relevant to this discussion.

. First, PTAs historically have provided the interface between schools, families and communities. Published reports document and describe the many forms PTA

activity has taken over the years.

A second model, of a more individualized nature, is that provided under the special education law, P.L. 94-142. Meetings between family members, older children, and educational and other professionals involved with developing a child's educational plan are a mandated part of the process.

Third, and growing in numbers, are Special Education Advisory Committees which exist in many communities to provide a forum for the many special concerns of families, community members, and the staff or administration of local special education services.

Individuals concerned with health care may want to identify and review these and other models in order to develop and adapt forums suited to their own particular needs. While such forums in health care settings are rare, they do exist: Boston Children's Hospital has had a Parent Advisory Committee for the past four years.

Summary

Consumer participation is a vital process and is an important component in quality health care. Parents are striving to become more informed and actively involved with those professionals and systems that intimately affect their own and their children's lives.

Families need the understanding and the support of health professionals to carry out these new roles: It cannot be done in isolation. While many health professionals are receptive to, and even encourage and initiate, such activities, others have not had the necessary training themselves and are not aware of the issues families face. Yet another difficulty is the fact that many traditional health settings were designed and built at a time when the roles for patients and parents were considerably different.

Involving parents within these settings as active team members means an active orientation is necessary for families as well as professionals. Overcoming "customary" ways of viewing parents and children as recipients of care takes a great deal of discussion of patterns of thinking and of evaluation of parent and professional responses.

Hospitals tend not to have the same sort of opportunities for discussion among parents, patients, and staff which are so common in education and other human service settings. This lack means there is no way for people in different roles to get to know each other, no way to know that concerns are shared, and no way to discuss how cooperation toward common goals might proceed.

In summary, as Gliedman and Roth have stated in *The Unexpected Minority: Handicapped Children in America:*

"In every handicap specialty it is essential that parent and professional actively work together on the child's behalf. Cooperation may be essential for medical reasons: medication that is not given by the child's parents is medication that may as well not be prescribed. Collaboration is also necessary because neither the parent nor the professional possesses a monopoly on the truth, and each can serve as a check on the shortcomings and limitations of the other. But before a partnership can genuinely exist, there must be give-and-take, mutual respect, and something like moral and cultural equality. Both the parent and the professional must attempt to understand the other's point of view, special moral concerns, and culturally determined priorities of the child." □

Gleidman, J. and Roth, W. *The Unexpected Minority: Handicapped Children in America.* New York: Harcourt Brace Javanovich, 1980. Pg. 145.

The following written materials, developed by the Parent/Professional Collaboration Project of the Federation for Children with Special Needs, are presently available. Write to the Federation for Children with Special Needs, 312 Stuart Street, Boston, MA 02116.

Monographs and Fact Sheets

Questions When Surgery is Recommended for your Child
Some Suggestions for Communication with Medical Personnel
Your Rights to Medical Records on Massachusetts
Preparing for Medical Testing
Medical Rights of Pediatric Patients and Parents in Massachusetts

Annotated Bibliographies:

Attitudes Toward Handicaps and Chronic Illness and Strategies for Coping
Communication and Partnership Between Parents and Professionals
Personal Accounts of Disability and Illness
Impact of a Parent Advisory Committee on Hospital Design and Policy
Care and Treatment Issues

Bibliography

Barnlund, Dean C. "The Mystification of Meaning. Doctor-Patient Encounters," *The Journal of Medical Education* Vol. 51, Sept. 1976.

Bilotti, Eugene. *Getting Children Home: Hospital to Community*, Workbook Series for Providing Services to Children with Handicaps and Their Families, Washington, DC: Georgetown University Child Development Center. 1984.

Chronically Ill Children and Their Families: Today's Challenge to Health and Education. (Vol. II). James M. Perrin, M.D., N. Hobbs, Ph.D. and H. Ireys, Ph.D. editors, Vanderbilt University Institute for Public Policy Studies. San Francisco: Jossey-Bass, Inc. To be published September, 1985.

Cousins, Norman. *Anatomy of an Illness as Perceived by the Patient: Reflections on Healing and Regeneration.* New York: Bantam. 1981.

Crocker, E. Serotkin, Ferguson, Finkel. "Hospital Politics and Change: The Art of the Sometime Possible." Association For the Care of Children's Health, *Conference Proceedings*, pp. 15-18. 1978.

Featherstone, Helen. *A Difference in the Family: Living with a Disabled Child.* New York: Basic Books. 1980.

Freedman, Steve A. Ph.D. *Brokering Power at the State Level for Child Health Care.* Workbook Series. Washington DC: Georgetown University Child Development Center. 1984.

Giving Families a Break - Strategies for Respite Care. Nebraska Respite Training Project. Omaha, NE: Meyer Children's Rehabilitation Institute, University of Nebraska Center. 1982.

Gleidman, J. & Roth, W. *The Unexpected Minority: Handicapped Children in America.* New York: Harcourt Brace Jovanovich. 1980.

Haar, Doris. *Power Brokering in the Community.* Workbook Series. Washington, DC: Georgetown University Child Development Center. 1984.

Harrison, Helen. *The Premature Baby Book: A Parent's Guide to Coping and Caring in the First Years.* New York: St. Martin's Press. 1983.

Haynes, U., M. Lowry, M. Schilling, and J. Siepp. *Staff Development Handbook: A Resource for the Transdisciplinary Process.* New York: United Cerebral Palsy, Inc. 1976.

Home Care for Children with Serious Handicapping Conditions: A Report on a Conference Sponsored by the Association for the Care of Children's Health and the Division of Maternal and Child Health, Public Health Service, U.S. Department of Health and Human Services. Linda Harteker, editor, Washington, DC: Association for the Care of Children's Health. 1984.

Howe, James. *The Hospital Book.* New York: Crown. 1981.

Issues in the Care of Children with Chronic Illnesses. (Vol. I). James M. Perrin, M.D. N. Hobbs, Ph.D. and H. Ireys, Ph.D. editors, Vanderbilt University Institute for Public Policy Studies. San Francisco: Jossey-Bass, Inc. To be published September, 1985.

Jones, Monica Loose. *Home Care for the Chronically Ill or Disabled Child: A Manual and Sourcebook for Parents and Professionals.* New York: Harper & Row, 1985

Korsch, Gozzi, Francis. "Gaps in Doctor-Patient Communication." *Pediatrics.* Vol. 42, No. 5, Nov. 1968

Lear, Martha Weinman. *Heartsounds.* New York: Simon & Schuster. 1980.

Magrab, Phyllis, Elder, J., Kazuk, E., Pelosi, J., & Wiegerink, R. *Developing a Community Team.* Washington, DC: American Association of University Affiliated Programs. 1981.

Masse, Suzzanne & Robert. *Journey.* New York: Alfred A. Knopf, 1975.

McCollum, Audrey, T. *The Chronically Ill Child: A Guide for Parents and Professionals.* New Haven: Yale University Press. 1981.

Medical Aspects of Developmental Disabilities in Children Birth to Three: A Resource for Special Service Providers in the Educational Setting. James A. Blackman, M.D., editor. Iowa: University Hospitals and Clinics Department of Pediatrics. 1983.

Murray, J.B. and Murry, Emily. *And Say What He Is: The Life of a Special Child.* Cambridge, MA: MIT Press, 1975.

Report of "Brook Lodge Invitational Symposium on the Ventilator Dependent Child." Mary M. Hunter, editor. 1984. (Copies available by writing to the Children's Home Health Network of Illinois, East 65th Street at Lake Michigan, Chicago, IL, 60649.)

Report of the Ad Hoc Task Force on Home Care of Chronically Ill Infants and Children. American Academy of Pediatrics. *Pediatrics*, 74, 434-436. 1984.

Report of the Surgeon General's Workshop on Children with Handicaps and Their Families. U.S. Department of Health and Human Services. DHHS

Publication #PHS-83-50194, 1983. (Available from the National Center for Education in Maternal and Child Health, 3520 Prospect St., NW, Washington, DC, 20057.)

The Parent Physician Relationship. Iowa: Iowa Pilot Parents, 1982. (Available for Iowa Pilot Parents, 1602 10th Avenue, North, P.O. Box 1151, Ft. Dodge, IA 50501.)

Treating Families in the Home: An Alternative to Placement. M. Bryce and J.C. Lloyd, editors. Springfield, IL: Charles C. Thomas, 1980.

Turnbull, H. Rutherford, III and Turnbull, A. *Parents Speak Out: Then and Now*, Second Edition. Columbus, OH: Charles E. Merrill, 1985.

Turnbull, H. Rutherford, III, and Turnbull, Ann, editors. *Parents Speak Out: Views from the Other Side of the Two-Way Mirror.* Columbus, OH: Charles E. Merrill, 1978.

Wolfensberger, Wolf. *The Principle of Normalization in Human Services.* National Institute on Mental Retardation. Toronto: Leonard Crainford, 1972.

The Association for the Care of Children's Health (ACCH) is an international, multidisciplinary organization which promotes the emotional and psychological well-being of children and their families in the community and in health care settings. The following is a partial list of ACCH resources for pediatric home care:

Activities for Children with Special Needs, 1980

Caring for Your Hospitalized Baby. (Pamphlet for parents)

Community Checklist for Care of Children with Special Needs

Guidelines for Developing a Community Network, 1984

Guidelines for Establishing a Family Resource Library, 1983

Home Care for Children with Serious Handicapping Conditions, 1984. (Compilation of articles on key issues in providing pediatric home care)

Hospital School Programs: Guidlelines and Directory, 1981

The Child and Health Care: A Bibliography, 1983

The Chronically Ill Child & Family in the Community. (Pamphlet in English and Spanish)

When Your Child Has a Life Threatening Illness. (Booklet for parents)

For complete list of available resources and ordering information contact Association for the Care of Children's Health, 3615 Wisconsin Avenue, Washington, D.C. 20016 (202) 244-1801.

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NEXT STEPS: Planning for Employment A Workshop for Parents

by *Winifred Anderson, Carolyn Beckett, Stephen Chitwood, and Deidre Hayden*
Parent Educational Advocacy Training Center, Alexandria, Virginia

For the past seven years, the ***Parent Educational Advocacy Training Center*** *in Alexandria, Virginia, has conducted educational advocacy courses for parents of disabled children. The purpose of these courses is to prepare parents to participate effectively in the special education process of referral, evaluation, eligibility, Individualized Education Program (IEP), and placement for their children with special needs. Parental participation in special education planning is required under the Education for All Handicapped Children Act, P.L. 94-142. Studies of the effectiveness of the courses in educational advocacy demonstrate that parents have gained knowledge and skills needed to promote the best interests of their children. Additionally, the studies indicate that school teachers and administrators perceive parents who have completed the training as being active, cooperative and influential participants in special education procedures.*

"Where will my son be in four years? What will he be capable of doing after high school?"

"Our daughter talks of her own paycheck some day. We think she can learn to hold a job, but she needs individual help. Is that possible? Are we asking too much?"

Such questions by parents reflect concern about their disabled children's future vocational opportunities. They anticipate their sons' and daughters' daily lives beyond the school setting with hopes and fears. Will their children be prepared to participate in the work world? Will these young adults find jobs in which they work to their potential? What should parents know and be doing now for their children to ensure a successful transition from the school setting to the world of work and adult life in the community?

The 94-142 generation is growing up. The confidence and effectiveness of parents trained to be advocates for their children under the umbrella of P.L. 94-142 wanes as their sons and daughters move into adolescence and look toward adult life. Families find overwhelming the myriad of public and private agencies involved in career education, the jargon used in vocational education and job training, and the jumble of local, state and federal laws affecting the training and employment of disabled individuals. This maze of special education, vocational education, rehabilitative services, and job training is a major barrier to parents wishing to secure for their disabled children maximum independence after leaving the public schools.

Current surveys and studies consistantly indicate that parents want information and training on how to obtain career education and employment opportunities for their disabled sons and daughters. Parents must acquire certain skills to be successful in working cooperatively with school professionals and other agency officials to advance the work capacities of their children with special needs.

NEXT STEPS: Planning for Employment is a fifteen-hour course designed by the Parent Educational Advocacy Training Center to assist parents in the long-range planning for their child's transition from school to work.

The design of *NEXT STEPS* took over a year. Development activities included a review of the literature, as well as extensive interviews with parents, current and former special education students, special educators, vocational educators, vocational rehabilitation admin-

continued on page 2

istrators and counselors, job training specialists and employers. A ten-member advisory committee comprised of parents, service providers and employers provided ongoing consultation regarding appropriate content and teaching methodology for the *NEXT STEPS* course.

Roles for Parents

Seven specific roles were identified for parents as their children prepare for the transition from school to an employment setting. *NEXT STEPS* was developed to provide parents with the necessary skills and information to fulfill the seven roles. A word of caution: while the roles parents may assume are numerous and critical, it is important to remember that **nobody does it all.** The strengths and needs of individual children and the strengths, skills, time and energy limitations of individual parents determine which roles they will fulfill. The various roles which parents explore in *NEXT STEPS: Planning for Employment* are described below.

I. Parents as Advocates for Career Education in the School Program

Career education is the process that prepares a student to participate in the worlds of work, family and community life. It facilitates each individual's potential for economic, social and personal fulfillment. First advanced as a national concept in 1971, the initial flurry over the importance of career education quickly diminished. Since then it has been incorporated into school curricula across the country only in a haphazard way. However, the nation's current employment forecasts and the demand for educational accountability have renewed the career education momentum. Valuable for all students, career education is particularly necessary for students in special education programs. The present reality is that disabled students tend to live in more closed worlds. They have fewer adult role models. With limited skills in incidental learning, these students need direct help to understand work possibilities and to create opportunities for real work experiences.

During the *NEXT STEPS* course, parents learn the four stages of career education: career awareness, career exploration, career preparation and career placement. Parents, frequently concerned about the balance between an academic and vocational curriculum, learn that career education does not necessarily replace the academic program. Work related skills and experiences may be infused into the academic program, or they may be taught at a separate time during the day.

The U.S. Department of Education reports that fewer than five percent of the students receiving special education have a career education goal or objective written into their Individualized Education Program (IEP). Parents' awareness of the option for career education coupled with active participation in their children's IEP meetings will change that statistic. During the *NEXT STEPS* course, parents learn how to integrate the curricula and objectives of the stages of career education into their child's IEP. A 1984 Colorado Department of Education follow-up study of 234 special education students recorded the students' strong regret that "critical community life skills" had not been a part of their education. Parents, recognizing the need for a functional, community-based career education curriculum, can become key players in bringing it about for their children and their school system.

II. Parents as Providers of Unique Information

Parents know many things about their children that are never reflected in school or agency records. They know what motivates their children, sends them into a frenzy, or catches and sustains their attention. Parents have been in the business of reasonable accommodation for a long time. They have, by necessity, found practical detours around roadblocks to achievement for their children. Such parental expertise is too valuable to be excluded from IEP and transition planning. Too often parents do not have confidence in the information they have about their children. They don't feel skillful in talking about this information with service providers. During the *NEXT STEPS* course, participants develop a personal work profile of their children. The profile provides a framework for organizing parents' knowledge of their children to share with others in a concise, timely manner. Using data from home observations and from school and agency records, parents record their children's personal traits, interests, aptitudes and work adjustment skills. Definitions and examples of each are given below.

- A **personal trait** is a distinguishing quality or personal characteristic. Examples include:
  1. prefers an orderly environment
  2. enjoys group activities
  3. curious about the way things work
  4. follows the lead of others
- An **interest** is a feeling of wanting to do or share in something. Examples include:
  1. watching and participating in sports
  2. playing with little children
  3. taking apart and putting together mechanical objects
- An **aptitude** is a natural ability, talent, or capacity for learning. Examples include:
  1. clerical aptitude (checking letters and numbers, matching names and numbers, math, reasoning, etc.)
  2. fine eye-hand coordination (using small tools, tracing, copying, etc.)
- **Work adjustment skills** are the behaviors and attitudes that enable a person to function in the role of

the worker. Examples include:

1. dependability (punctuality, regular attendance, keeps schedule, etc.)
2. inter-personal relations (works without physical interference to others, cooperates with supervisor, communicates adequately with coworkers, etc.)
3. personal appearance (clean body, neat clothes, cut and combed hair, etc.)

The personal profile provides parents and others with organized information relevant to a student's future role as a worker. This information often corrects out-of-date assumptions about what a child can or can't do and yields a more realistic picture of a student's employment-related strengths and areas needing change. In this way, parents begin to view and to articulate a sense of their son or daughter as a worker, rather than a youth with limited academic capabilities.

Professionals in the employment training business know that a successful match of a job and a worker depends on accurate knowledge of an individual. Vocational rehabilitation professionals are turning more and more to informal assessments of a client's functioning in work related areas to determine eligibility and to formulate rehabilitation plans. Information provided by parents has proven to be important in special education planning. The practical insights and information parents have about their sons and daughters also is providing valuable as they work with professionals to plan and implement successful transitions from school to the workplace.

III. Parents as Role Models

Parents communicate both spoken and unspoken messages to their children about the value of work both inside and outside the home. Work is an individual's primary way of fulfilling the human demands for activity, productivity, achievement and social interaction. For most people, work has more positive meaning than any other facet of life. By consciously emphasizing the benefits and responsibilities of work, parents of children with special needs promote the important assumption that their son or daughter will be a member of working society. When parents send the message, "There is a world of work out there and you are going to be a part of it," they enhance their children's self-image and encourage their interest in employment possibilities.

During the *NEXT STEPS* course, parents consider the range of employment opportunities for their children. They learn about the nineteen career clusters and specific job characteristics identified by the Department of Labor in the *1984-85 Occupational Outlook Handbook*. They become familiar with the work settings available for their children after they leave the secondary school. Such work opportunities exist to greater or lesser degrees in various communities. These options range from least to most restrictive environments and include:

1. **Competitive Employment:** Regular jobs paying at least minimum wage, in real work settings with non-disabled persons (can be full- or part-time jobs.)
2. **Post-Secondary Education:** Formal education after high school that takes place in a four-year college or university, community college, post-secondary vocational school or through an apprenticeship program.
3. **Supported Work Model:** A model of competitive employment that offers individualized job placement, job-site training and follow-up services for the employee by a professional job counselor. Follow-up services may be lifelong. Becoming more and more widespread, supported work is an innovative concept that provides individuals with moderate and severe disabilities the opportunity for competitive employment. It eliminates old stereotypes that assume people with certain disabilities or IQs are able to perform only the most simplistic jobs in an environment segregated from normal workers.
4. **Enclave:** A group of disabled persons performing work in a regular place of business. The work is done in a segregated location within the business setting. Full supervision is provided by a service agency. Salaries may be either regular wages or piece rate wages.
5. **Transitional Job Training:** A relatively short-term program (under two years) designed to provide the vocational services necessary to help an individual obtain employment on a competitive basis.
6. **Sheltered Employment:** Employment in a supervised setting with client productivity equaling at least 50% of an average worker. In a sheltered workshop, workers with disabilities are segregated from non-disabled workers. Work is most often contract work with workers paid on a piece rate basis.
7. **Work Activity Center:** A self-contained setting where staff members assist disabled persons with activities that emphasize vocational skill development and some community skill training.
8. **Developmental Center:** A self-contained setting where staff members assist clients with personal care and maintenance and with the development of community living skills. A limited amount of vocational training is provided.

Too often inappropriate work-related behaviors prevent a disabled person who has masterd a specific vocational skill from successfully getting and keeping a job.

Work adjustment skills include work habits, self-confidence, interpersonal relations and reactions to authority. These work skills, behaviors and attitudes are too frequently missing in IEP planning and implementation. Parents and professionals, working together to teach and reinforce these associated work requirements, greatly increase a young adult's chances of getting and keeping a job. Parents are the primary role models for their children in the areas of work adjustment skills, behaviors and attitudes.

IV. Parents as Case Managers

Often the good intentions of agreements and collaborative efforts between various agencies are not fully met. As a result, parents find themselves with the responsibilities of suggesting, reminding, confirming and checking up. Service providers are busy. They enter at different points in a student's life. Teachers, counselors or trainers may have a long or brief relationship with a student or client depending on their own personal and professional life changes. The better grasp parents have on the total picture of their child's long range transition plan and on the participants responsible for that plan, the less likely that important information, deadlines and opportunities will fall through the cracks.

In the *NEXT STEPS* course, parents practice using a Career Education Planning Chart. This form can serve as an informal transition plan to structure a smooth change from the school environment to the work environment. As a management tool, it assists parents in their role as case managers by providing a framework for writing (1) brief statements describing their sons' or daughters' work-related interests, aptitudes traits and associated work skills; (2) career education goals and objectives; and (3) an outline that identifies the roles and responsibilities of the student and parents as well as the educators and service providers. Including these individuals in the long-range planning can help to ensure that students with disabilities will have the necessary skills to move from school to work.

V. Parents as Risk Takers

How many times professionals are heard saying, "Oh, if those parents could just let go!" Letting go is the key to independence. Letting go provides children and young adults with opportunities to use public transportation, spend their own money, call a boy or girl on the phone, join Little League, attend the football game alone, etc., etc. Parents know that letting go is necessary for their children's growth and maturity, but letting go is hard to do. For too long, families have received much more information about the abilities and skills their children **lack.** After a lifetime of messages about what their children can't do, parents need assistance to envision what their children are capable of accomplishing in their adult lives. They need to learn that with appropriate supports in place, their children's strengths can be tapped and their contributions to society can be realized.

Recent studies have indicated that the opposition of parents is an obstacle between their adult sons' and daughters' current placements in sheltered workshops and new opportunities for competitive employment. A recent conversation with a team of competent, caring service providers underscored this point. The staff was very excited about a community-based job for a twenty-seven year old client who had been in a sheltered workshop for the past six years. The staff was also very frustrated by the client's parents' lack of enthusiasm and an expressed disbelief that their adult son could succeed in the proposed job. The professionals felt angry because the parents were clinging to the status quo, thereby standing in the way of an opportunity to provide growth in their son in a much less restrictive environment.

In talking with the staff, however, several critical questions arose. Were the parents aware that their son's Medicaid and SSI benefits would not be eliminated? Did the family understand that their son would have a trainer and friend to assist him every day in moving about on public transportation? Had the parents visited the job site? Did they know that a job coach would be with their son everyday? Had they met the job coach? Were they aware that their son's slot in the sheltered workshop would still be available to him if the new position didn't work out? The answer to each of these questions was either a definitive "No," or a fuzzy "We're not sure." It was readily apparent that while intensive preparation for transition had been completed with the young man, the family was not involved in the planning. They were left with their many concerns unaddressed.

Letting go is easier if parents are involved early as answers are found to the questions, "Letting go to where?" and "Letting go with the supports in place?" Some assurance of the continuity of the new and less traditional services allows parents more freedom to let go.

VI. Parents as Financial Planners

It is encouraging to know that policy makers at the federal level are working to change the disincentives currently attached to federal financial assistance programs. Also encouraging are the quality benefit packages becoming available to disabled persons participating in model supported work programs. Until financial disincentives are removed, however, and until model programs exist in all communities, young adults with disabilities and their parents will continue to make extraordinarily difficult decisions. They struggle to find a balance between the rewards of employment and the need for immediate and long term

financial security. Does Sally accept the minimum wage job that offers no medical benefits, yet causes the loss of her eligibility for Social Security Income and Medicaid? Or does she stay home with her SSI and medical insurance intact, with her daily routine lacking in the stimulation, growth and satisfaction that work provides?

To make these difficult decisions, parents need assistance. They require help in gathering and understanding accurate information about eligibility requirements for financial assistance, and the benefits of paid versus non-paid work. With help from knowledgeable service providers, families can assess the costs and benefits of their sons' and daughters' becoming grown children. In addition, professionals can inform parents about wills, trusts and guardianships. Once understood, this information helps parents establish guidelines for making important decisions regarding the financial needs of their sons and daughters throughout their adult lives. Most importantly, professionals can offer families their respect—respect for the individuality of family priorities, respect for the serious and difficult financial questions families must address and respect for the solutions families finally reach in financial areas.

VII. Parents as Program Advocates

The full range of services special education students need to make successful transitions from school to work are not yet in place. Career education is not infused into all school curricula. Few students with disabilities are participating in regular vocational education programs. Special education and vocational rehabilitation services seldom are coordinated. Most communities have only sheltered employment options, accompanied by long waiting lists, for disabled citizens. Far, far too many disabled youths and adults sit at home or in institutions without meaningful employment and participation in community life.

Many changes are still needed, and parents are integral to the process of change. As partners with educators, service providers, employers and politicians parents can advocate for new ways to provide appropriate preparatory services for young people. Parents have proven themselves effective in lobbying for legislation and in shaping public policy. Vital involvement in the passage and maintenance of P.L. 94-142 earned parents a strong reputation. Additional challenges must now be met at the federal, state and local levels to ensure adequate programs in the community and in the local school systems.

In the *NEXT STEPS* course, participants discuss specific strategies for change at the school, community, state and federal levels to promote career education programs. The list becomes long and overwhelming. So when considering the magnitude of the task, it is important to repeat the message: **nobody does it all.** Many parents and professionals have given unending time and talents to the formation of P.L. 94-142. Contributions come in many forms, reflecting individual strengths, interests and needs. As classroom volunteers, letter-writers, public speakers, fund raisers, committee members, participants in IEP meetings, homework helpers, etc., these people link the intent of P.L. 94-142 to the needs of individual children. Families, service providers and public officials, working together once more, will build on current accomplishments to create transition programs for disabled youth that are ethically, developmentally and fiscally sound.

Summary

There is a growing national consciousness supporting the rightful membership of persons with disabilities in the mainstream work force. As in other movements, the breakthrough will be complete only when equal employment opportunities for disabled persons are taken for granted by the citizen on the street. Disabled students, their parents, educators and other concerned persons are the force behind the current changes in attitudes and policies. To increase their effectiveness as promoters of change, these individuals require assistance in gathering pertinent information and developing appropriate skills.

The *NEXT STEPS* course provides a way for parents to gain the necessary knowledge and skills to fulfill their needed roles in their children's passage to work and adult life. For example, one mother, after participating in the *NEXT STEPS* course, stated, "I didn't have a vision of my daughter's work potential. Now I think I have a more realistic picture of her options and what we need to do to get there." A father commented, "My wife and I are now talking about long range plans ... we hadn't talked to each other before about our individual hopes and concerns." Another person said, "My autistic son is going to junior high school next year. You can be sure that his new IEP will include career education goals and objectives."

Currently, *NEXT STEPS:* Planning for Employment is being conducted for parents by the staff of the Parent Educational Advocacy Training Center in Alexandria, Virginia. In addition, seven parent-professional teams trained by the Parent Center to conduct *NEXT STEPS* are now giving the course in communities in Vermont, New Jersey, Maryland, South Carolina and Virginia. In November, 1985, additional teams will be trained to conduct *NEXT STEPS:* Planning for Employment.

For further information about *NEXT STEPS*, contact the Parent Educational Advocacy Training Center, 228 South Pitt Street, Suite 300, Alexandria, Virginia 22314, Phone (703) 836-2953.

A Bibliography for Career Education

Directory of College Facilities and Services for the Handicapped, 1983. Available from Oryx Press, 2214 North Central at Encanto, Pheonix, AZ 85004.

This directory lists, state-by-state and province-by-province, colleges and universities in the U.S. and Canada and their programs accommodations for handicapped students. The directory was compiled from responding schools and includes both large and small colleges. Each entry includes information on level of degrees conferred, disabled student population, facilities, and special services available for handicapped students.

A Directory of Public Vocational-Technical Schools and Institutes in the U.S.A., 2nd edition, 1984-85. Available from Minnesota Scholarly Press, P.O. Box 224, Manhato, MN 56001.

This directory lists public schools and institutes offering post secondary, non-degree occupational education. It provides names and addresses of schools, director's names and telephone numbers, and complete program/course listings. It is arranged state-by-state and has an excellent index.

A Guide to Post-Secondary Educational Opportunties for the Learning Disabled, Dian M. Ridenour, 1981. Available from Time Out to Enjoy, Inc., 715 Lake Street, Suite 100, Oak Park, IL 60301

This directory is nationwide in scope (including Canada) and divided into sections containing various programs, i.e., colleges with special formalized LD programs; schools with a learning lab and a master's level teacher for LD; schools willing to make accommodations on a case-by-case basis.

A National Directory of Four Year Colleges and Post High School Training Programs for Young People with Learning Disabilities, 1984. Available from Partners in Publishing, Box 50347, Tulsa, OK 74150

This directory lists educational facilities that are able and willing to adapt curricula and give special attention to students with perceptional disablities.

Occupational Outlook Handbook, U.S. Department of Labor, Bureau of Labor Statistics, 1984-85 edition. Available from (Bulletin 2205), Superintendent of Documents, U.S. Government Printing Office, Washington, D.C. 20402.

The handbook lists occupations, grouped by career cluster, and gives a good summary for each including: what the work is like, education and training required, advancement possibilities, earnings and the job outlook. There is an introductory section forecasting what the future job market will look like.

Of Work and Worth: Career Education for the Handicapped, Pamela Gillet, 1981. Available from Olympus Publishing Company, 1670 East 13th Street, Salt Lake City, UT 84105.

An easy to read textbook which discusses career education planning and activities as an integral part of the education program in grades K-12.

Preparing for the World of Work, Frank Gillet, 1983. $4.95. Available from F. R. Publications, 1103 St. Paul Drive, Merrill, WI 54452, (715) 536-2836.

This workbook provides text and skill building exercises to acquaint the student with essential information concerning the work world. Topics such as Social Security, locating employers, job interviews, work permits and job responsibilities are included.

Resource Guide: Vocational Counseling for the Handicapped, T. H. Hohenskil and C. Maddy-Bernstein. Available from Virginia Vocational Guidance Programs, College of Education, Virginia Tech, Blacksburg, VA 24061

An inexpensive resource guide including several hundred annotated listings of articles, books, audio visual materials, staff training materials and organizations concerned with career education of students with special needs.

See Me More Clearly, Joyce Slayton Mitchell, 1980. Available from Harcourt Brace Jovanovich, Inc. 757 Third Avenue, New York, NY 10017

A book written to help teenagers with physical disabilities become more financially and emotionally independent. Restoring, developing and maintaining a positive self-concept in order to make sound educational and career decisions is the dual purpose of this book.

SUCCESS: Sources to Upgrade the Career Counseling and Employment of Special Students, J. H. Lombana. Available from Center for Studies in Vocational Education, Florida State University, Tallahassee, FL 32301

SUCCESS consists of a series of handbooks that provide practical information for school counsellors on the career guidance of disabled students. Each SUCCESS handbook is concerned with a different handicapping condition.

What Do You Do After High School? Available from Skyer Consultation Center, P.O. Box 321, Rockaway Park, NY 11694.

A nationwide guide to residential, vocational, social and collegiate programs serving adolescents, young adults and adults with learning disabilities. Original book lists over 350 programs, with a supplement listing an additional 150 programs. $29.95 for original and supplement: $12.95 for supplement only.

Whatever You Decide, Jennifer Mohr, 1983. Available from Advocating Change Together, Inc., 1509 Nicollet Avenue, Minneapolis, MN 55403, (612) 874-1133.

A workbook for teaching people who have mental retardation on how to make choices and assert themselves.

Parent Training Resources

The Technical Assistance for Parent Programs (TAPP) Project, a project of the National Network of Parent Centers, recently surveyed the Parent Training and Information Projects nationwide to collect information on parent training activities dealing specifically with the transition of young people with disabilities from school to world and life in the community. The following parent projects are particularly concerned with promoting parent involvement in assisting students with disabilities to be prepared for and find appropriate employment:

Parent Information Center of Delaware, Inc.
Patricia Gail Herbert, Project Director
193 West Park Place
Newark, DE 19711
(302) 366-0152

A five-month workshop teaches parents to clearly identify vocational needs, incorporate vocational information into the IEP, and identify and use all relevant state resources for young adults ages 16-21.

Parents Educating Parents Project/
Association for Retarded Citizens
Mildred J. Hill, Project Director
1851 Ram Runway, Suite 102
College Park, GA 30337
(404) 761-2745/761-3150
Contact Person: Carla Putnam

A full-day workshop describes all relevant federal, state and local services and how to access them. A "Consumer Guide to Vocational Opportunities" is being developed to accompany the workshop.

Coordinating Council for Handicapped Children
Charlotte DesJardins, Project Director
2208 State Street, Room 412
Chicago, IL 60604
(312) 939-3513

A four-hour workshop on transition is conducted annually. A weekly basic training workshop of four to five hours includes transition and employment related information. Supplemental materials accompany both types of workshops.

PARENTS+PLUS/Kentucky Coalition for Career
and Leisure Development
366 Waller Avenue, Suite 119
Lexington, KY 40504
(606) 278-4712

Monthly trainings equip parents to identify and access adult services, become familiar with eligibility requirements, and to assess functional skill level for their children. Legislative issues, adaptive devices and parents' future planning are discussed.

PACER Center, Inc.
Marge Goldberg and Paula Goldberg,
Project Directors
4826 Chicago Avenue South
Minneapolis, MN 55417
(612) 827-2966
Contact Person: Marge Goldberg

A workshop is being developed and piloted which focuses on special education, vocational education and rehabilitation. It will inform parents about programs, opportunities, issues and guidelines. A direction service guide on transition is being developed for state departments of education.

New Hampshire Parent Information Center
Judith Raskin, Project Director
P.O. Box 1422
Concord, New Hampshire 03301
(603) 224-7005

Three major projects include Vocational Advocacy Training, and Annual Conference which includes several workshops on transition and follow up sessions for individuals, and "Building," a workshop series. The Vocational Advocacy Training is 65 hours long and includes information on vocational education, assessment, rehabilitation, post high school opportunities, list of colleges and schools which provide jobs. "Building" includes 3 hours on transition issues. Handouts include a checklist of vocational assessment components and vocational options.

Western New York Association
For the Learning Disabled
Donald N. Policella, Project Director
190 Franklin Street
Buffalo, New York 14202
(716) 866-1135
Contact Person: Joan M. Watkins

"Managing Transition," an eight-week training (2½ hours per week), describes what local agencies do and do not provide. An on-the-job training program helps parents find out about the next step of their child's program and the people who will be instructing. Specific transition information needs of participants are addressed.

Southwest Ohio Coalition for
Persons with Disabilities
Thomas Murray, Project Director
3333 Vine Street
Cincinnati, Ohio 45220
(513) 861-2400

Two major workshops for parents and professionals focus on the need for a functional curriculum starting at an early age, to actually getting a job. Teams are developed to explore transition strategies. Included on team are parents, special education directors, teachers,

SOC board members. In addition to the workshop format, a transitional model program is being developed to provide service to sixty people with disabilities.

Ohio Coalition for the Education of Handicapped Children
Parent/Educator Team Training Project
Margaret Burley, Project Director
933 High Street, Suite #200H
Worthington, Ohio 43085
(614) 431-1370
Contact Person: Ellen L. Combs

The project is planning a transition "Kickoff" Conference with the Governor's Special Education Advisory Council for October, 1985. This conference will develop a list of recommendations for the Superintendent of Public Instruction to be incorporated into a state action plan. The conference will follow a two-day workshop format, with the first day devoted to the presentation of existing, exemplary vocational education and transition programs. These examples will serve as a basis for developing the list of recommendations for the state superintendent. It is anticipated that this conference will be the forerunner of many regional conferences held throughout the state.

Vermont Vocational Training Network
Joan Sylvester, Project Director
Vermont Association for Retarded Citizens
Champlain Mill #37
Winooski, VT 05405
(802) 655-4016
Contact Person: Connie Curtin

A project has been developed for parents, consumers and professionals to establish a statewide training network in transition, to develop and disseminate training materials and to conduct training workshops. This project emphasizes the need for communication, cooperation and collaboration among parents, consumers educators and adult service providers.

Federation for Children with Special Needs
312 Stuart Street, 2nd Floor
Boston, Massachusetts 02116

Washington, PAVE
Martha Gentili, Project Director
1010 South I Street
Tacoma, WA 98405
(206) 272-7804
Contact Person: Jo Butts

Parent programs on formal transition planning are operating at two high schools. At the request of parent groups, PAVE presents a two-hour session on planning ahead, supplying specific packages of materials. Each session is tailored to the specific needs of the parent group. A pilot program is also being developed with Vocational Rehabilitation and Special Education.

Parent Education Project
Liz Irwin, Project Director
c/o United Cerebral Palsy
154 West Wisconsin Avenue, Room 308
Milwaukee, WI 53202
(414) 272-4500

"Looking Ahead," a ten-hour workshop, is designed to make parents aware of the career education process, increase their awareness of the importance of vocational objectives in the IEP, familiarize them with the adult service delivery system, and identify ways to encourage school systems and adult service systems to meet students' needs.

The **National Network of Parent Centers** is coordinated by the **Federation for Children with Special Needs**
312 Stuart Street, Boston, Massachusetts 02116

Martha H. Ziegler, Executive Director
Janet R. Vohs, Editor

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